



2016

Rehabilitation, Education, and the Integration of Individuals with Severe Brain Injury into Civil Society: Towards an Expanded Rights Agenda in Response to New Insights from Translational Neuroethics and Neuroscience

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Recommended Citation

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Rehabilitation, Education, and the Integration of Individuals with Severe Brain Injury into Civil Society: Towards an Expanded Rights Agenda in Response to New Insights from Translational Neuroethics and Neuroscience

Megan S. Wright and Joseph J. Fins*

Abstract: Many minimally conscious patients are segregated in nursing homes, and are without access to rehabilitative technologies that could help them reintegrate into their communities. In this Article, we argue that persons in a minimally conscious state or who have the potential to progress to such a state must be provided rehabilitative services instead of being isolated in custodial care. The right to rehabilitative technologies for the injured brain stems by analogy to the expectation of free public education for children and adolescents, and also by statute under the Americans with Disabilities Act and under Supreme Court jurisprudence, namely the leading deinstitutionalization case, *Olmstead v. L.C.* ex rel. *Zimring*.

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TABLE OF CONTENTS

TABLE OF CONTENTS.....	234
INTRODUCTION.....	236
I. THE PROBLEM OF LACK OF ACCESS TO REHABILITATION FOR MINIMALLY CONSCIOUS PATIENTS	240
A. MINIMALLY CONSCIOUS STATE DEFINED	240
1. COMA	241
2. VEGETATIVE STATE.....	241
3. MINIMALLY CONSCIOUS STATE	242
B. IMPORTANCE OF REHABILITATION FOR PERSONS IN A MINIMALLY CONSCIOUS STATE.....	243
C. PERSONS IN A MINIMALLY CONSCIOUS STATE OFTEN LACK ACCESS TO REHABILITATION	245
D. CONSEQUENCES OF LACK OF ACCESS TO REHABILITATION FOR PERSONS IN A MINIMALLY CONSCIOUS STATE	247
E. HOW THE INJURED BRAIN IS SIMILAR TO THE DEVELOPING BRAIN.....	249
II. IMPERATIVE TO PROVIDE REHABILITATION TO THE INJURED BRAIN ...	251
A. BY ANALOGY TO EXPECTATION OF ACCESS TO FREE PUBLIC EDUCATION	251
1. EXPECTATION OF ACCESS TO FREE PUBLIC EDUCATION	251
2. REHABILITATION OF AN INJURED BRAIN IS SIMILAR TO EDUCATION OF A DEVELOPING BRAIN	256
3. IF UNDERSTOOD AS EDUCATION, MINIMALLY ADEQUATE REHABILITATION OF INJURED BRAIN IS ETHICALLY COMPELLED.....	257
B. BY STATUTE AND CASE LAW.....	259
1. PURPOSE OF THE REHABILITATION ACT OF 1973, ADA, ADAAA, AND <i>OLMSTEAD</i>	259
2. HOW LACK OF ACCESS TO REHABILITATION FOR THOSE IN MCS VIOLATES THE ADA AND <i>OLMSTEAD</i>	267
3. LEGAL REMEDIES AVAILABLE TO PERSONS WITH DOCs UNDER THE ADA.....	272
4. COUNTERARGUMENTS AND REBUTTALS	275

A RIGHTS AGENDA FOR SEVERE BRAIN INJURY

III. REFORMS TO REALIZE THE RIGHT TO REHABILITATION.....	277
A. PROPOSED CHANGES TO MEDICARE POLICIES	277
B. CAPABILITIES APPROACH	279
C. COUNTERARGUMENTS AND REBUTTALS	281
CONCLUSION	285

INTRODUCTION

“[N]ew insights and societal understandings can reveal unjustified inequality within fundamental institutions that once passed unnoticed and unchallenged”¹

As neuroscience evolves, the law is called upon to respond. In this Article, we focus on the rights of people with severe brain injury and subsequent disorders of consciousness. In particular, we focus on the right to rehabilitative technologies to aid in communication, which will aid in community integration. The arguments we put forth in this Article are responsive to advances in translational neuroscience.

This Article examines how changing medical practice and developments in neuroscience create new classes of persons with disabilities. Given the lack of categories and conceptualizations of the existence and needs of such persons, the law needs to respond and address their civil rights. We aim to apply neuroscience to law in a way that expands civil liberties.²

In the last decades of the 20th century, medicine has evolved to save the lives of patients with traumatic brain injuries who otherwise would have died or ended up in a permanent vegetative state as a result of their injuries. When a person has a traumatic brain injury, the brain swells. Because the skull does not provide room for the swelling, the brain herniates downward, potentially resulting in death or a persistent vegetative state.³ New techniques have advanced to manage elevated intracranial pressure, however, and now part of the skull can be removed (i.e., craniotomy and craniectomy).⁴ These medical advances saved lives, but injured persons are often profoundly disabled. Some are left with a disorder of consciousness, such as the vegetative state or minimally conscious state.⁵ The vegetative state is well known through landmark court cases, but the minimally conscious state less so.

1 *Obergefell v. Hodges*, 135 S. Ct. 2584, 2603 (2015).

2 In contrast, the neuroscience, neuroethics, and law agenda is dominated by scholars and funders who focus on what some call “criminal neuroscience.” See, e.g., *MacArthur Foundation Research Network on Law and Neuroscience*, VAND. U.L. SCH. (2016), <http://www.lawneuro.org>.

3 M. Ross Bullock et al., *Introduction*, 58 NEUROSURGERY (SUPPLEMENT) S2-1, S2-1 (2006), http://neurosurgery.hr/wp-content/uploads/2012/08/Surgical_Guidelines_article_2.pdf.

4 *Id.*

5 Technology both solved a problem in this case—preventing death—and created a problem—the existence of the minimally conscious state. Technology is now responding to the minimally conscious state, aiming to restore consciousness and communication. For a description of the relationship between technology and neuroethics, see Joseph J. Fins, *Neuroethics and the Lure of Technology*, in *THE OXFORD HANDBOOK OF NEUROETHICS* 895, 904 (Judy Illes & Barbara J. Sahakian eds., 2011) [hereinafter Fins, *Technology*] (“Technology, remember, is a queer thing; it brings you great gifts with one hand, and it stabs you in the back with the other.”).

The minimally conscious state was formally identified as a new diagnostic category in 2002.⁶ Persons in a minimally conscious state have intermittent and inconsistent evidence of consciousness that may or may not manifest behaviorally, and such persons may be mistaken for vegetative.⁷ The advent of this category was made possible by clinical advances discussed later in the Article, and there are resulting ethical, policy, medical, and legal questions.

We are especially concerned in this Article with the legal issues, in particular the lack of appropriate medical and rehabilitative treatment for persons in a minimally conscious state, and how this may violate the Americans with Disabilities Act⁸ and be inconsistent with the putative right to education. Currently, most minimally conscious patients “remain sequestered in nursing homes, incompletely diagnosed . . . at the margins of society,”⁹ without access to rehabilitative technologies that could help integrate them back into their communities.

In this Article, we assert that when there is potential for recovery of consciousness, there is a right to rehabilitative technologies for the injured brain. This right stems by analogy to the expectation of free public education for children and adolescents, and also by statute under the Americans with Disabilities Act¹⁰ and under Supreme Court jurisprudence, namely the leading deinstitutionalization case, *Olmstead v. L.C. ex rel. Zimring*.¹¹ Persons in a minimally conscious state or who have the potential to progress to such a state must be provided rehabilitative services instead of being segregated and isolated in custodial care.

Our argument proceeds as follows. In Part I of this Article, we describe how patients in the minimally conscious state often lack access to rehabilitative

6 See Joseph T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349 (2002).

7 See Joseph T. Giacino et al., *Disorders of Consciousness After Acquired Brain Injury: The State of the Science*, 10 NATURE REV. NEUROLOGY 99, 100 (2014).

8 The minimally conscious state is currently not a category reflected in the law, unlike the permanent vegetative state, the condition at the forefront of some of the most well-known right-to-die cases, or other medical conditions involving similar levels of cognitive impairment due to degenerative diseases such as Alzheimer’s or due to developmental disorders. Unlike the permanent vegetative state or Alzheimer’s Disease, persons in a minimally conscious state may actually improve, and unlike persons with a developmental disorder, persons in a minimally conscious state previously had capacity and thus had prior wishes. These differences present new questions for law.

9 Joseph J. Fins, *Border Zones of Consciousness: Another Immigration Debate?*, 7 AM. J. BIOETHICS 51, 52 (2007) [hereinafter Fins, *Border Zones*]; see also JOSEPH J. FINS, RIGHTS COME TO MIND: BRAIN INJURY, ETHICS, AND THE STRUGGLE FOR CONSCIOUSNESS (2015) [hereinafter FINS, *RIGHTS COME TO MIND*] (exploring shortcomings in society’s treatment of individuals in a minimally conscious state).

10 42 U.S.C. §§ 12101-12213 (2012).

11 527 U.S. 581 (1999).

technologies that have been increasingly shown to have the potential to help these patients recover a degree of functional status. In this section, we first define the minimally conscious state, and contrast it with other disorders of consciousness, such as comas and the vegetative state. We then describe investigational and therapeutic drugs and technological innovations that have been shown to have a beneficial effect on some patients with a disorder of consciousness. We next note the reasons why patients do not receive such interventions, and the negative consequences of this lack of access or societal neglect. We conclude this section by previewing our argument that rehabilitating the injured brain can be analogized to educating children whose brains are developing.

In Part II of this Article, we expand upon an argument made in the book *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness*.¹² We assert that there is a right to rehabilitation for persons with disorders of consciousness. We first argue that given the similar developmental processes that occur in the maturing brain and the recovering brain, the legally created expectation of free public education, which is so important to fulfilling the potential of the maturing brain, should be extended to individuals with severe brain injury where a regenerative process recapitulates an earlier developmental script.¹³ Given the homology of developmental biology and brain repair, and the utility and ubiquity of education in early life, we argue that restorative efforts directed at the injured brain are better understood as an educational process than solely as a rehabilitative act.¹⁴ Expanding our conception of rehabilitation to include education places these efforts beyond a mere medical care entitlement and into the sphere of legally created expectations, which are both grounded in statute such as the Individuals with Disabilities Education Act (IDEA)¹⁵ and also No Child Left Behind,¹⁶ constitutional analysis, and common sense.

We then argue that based on the Americans with Disabilities Act (ADA), including subsequent amendments to and case law interpreting the Act, there is a statutory right to rehabilitation for brain-injured persons with disorders of consciousness receiving treatment from healthcare facilities and residing in custodial care facilities. Currently, without such access to rehabilitative technologies, conscious or potentially conscious persons are segregated and isolated in custodial care facilities, and are not receiving necessary treatment, which violates the purpose of the ADA.¹⁷ Furthermore, persons with disorders of

¹² FINS, RIGHTS COME TO MIND, *supra* note 9.

¹³ *Id.* at 306-07.

¹⁴ *Id.*

¹⁵ Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-82 (2012).

¹⁶ No Child Left Behind (NCLB) Act of 2001, 20 U.S.C. § 6301 (2012).

¹⁷ FINS, RIGHTS COME TO MIND, *supra* note 9, at 289-92.

consciousness are not given access to auxiliary aids (such as drugs, devices, neuroimaging, neuroprosthetics, and rehabilitation) that would assist them in communicating with their healthcare providers and caregivers, which violates the statutory and regulatory requirements of the ADA. Finally, given that the ADA was amended to expand rights to the disabled, and was modeled after and is a legacy of civil rights legislation, we should expect that courts will increase protections and rights for this newly recognized class of disabled persons with their unique communication needs. We do not argue for further amendments to the ADAAA, but rather the application of this legislation to persons with disorders of consciousness, and we describe how remedies under the ADA are potentially available to persons with disorders of consciousness who lack access to rehabilitative technologies.

In Part III of this Article, we explore some necessary changes to implement the content of a right to rehabilitation beyond providing rehabilitative technologies for those with disorders of consciousness. We suggest some policy changes, such as changing Medicare payment criteria, which would make more persons with disorders of consciousness eligible for specialized rehabilitative care. It is important to note, however, that entitlement reform is a necessary but not sufficient component of reform.¹⁸ Such reform does not address the fundamental marginalization of persons with disorders of consciousness, who are disregarded by society and the law. The application of a statutory right to reasonable accommodations, which for this population is access to rehabilitative technologies, is likewise insufficient. Persons with disorders of consciousness need both a right to rehabilitation, which symbolically asserts that their integration into the community is important, as well as entitlement reform that provides one avenue for them to access such rehabilitation.

Thus, we explore the capabilities approach espoused by social scientists and philosophers such as Amartya Sen,¹⁹ Martha Nussbaum,²⁰ and Sridhar Venkatapuram.²¹ We suggest here and elsewhere²² how this school of thought

18 *Id.* at 287 (“And even now, I have no doubt that harmonizing time frames of recovery and reimbursement streams would advance care, decrease capricious denials, and lead to rehabilitation trials of appropriate duration. But . . . I am not convinced that reimbursement reform will happen without fundamentally changing how we view the minimally conscious, their needs, and their place in society.”).

19 *See generally* AMARTYA SEN, *COMMODITIES AND CAPABILITIES* (1999) (relating ability to function to overall wellbeing).

20 *See generally* MARTHA NUSSBAUM, *CREATING CAPABILITIES: THE HUMAN DEVELOPMENT APPROACH* (2013) (arguing for measures of progress that account for the basic human needs for dignity and self-respect).

21 *See generally* SRIDHAR VENKATAPURAM, *HEALTH JUSTICE* (2011) (applying the “capabilities approach” to health and health care, asserting that there exists a moral right to be healthy).

22 FINS, *RIGHTS COME TO MIND*, *supra* note 9, at 293-94; Joseph J. Fins et al., *Whither the*

bridges the right to rehabilitation with the technologies that can enable this process leading to the furtherance of the civic integration of persons with disorders of consciousness, which is what truly enhances freedom, dignity, and community for persons with brain injury and disorders of consciousness.

Finally, we acknowledge that there is a cost to implementing this right to rehabilitative technologies, but assert that the ADA limits the effect that cost considerations can have in denying access to accommodations and modifications, and also point to other considerations in a cost-benefit analysis that may be useful. We also address concerns that this issue is not yet ripe given the experimental nature of some of the rehabilitative technologies we describe. Our arguments should be understood as relevant to the current state of medical technologies, but also as anticipating future scientific advances; our legal theories are anticipating changes in medical practice.

We conclude by noting that if a right to rehabilitation of the injured brain is recognized, such recognition would also be in line with recent Supreme Court jurisprudence articulating ideals of dignity for all.²³

I. THE PROBLEM OF LACK OF ACCESS TO REHABILITATION FOR MINIMALLY CONSCIOUS PATIENTS

A. Minimally Conscious State Defined

Disorders of consciousness (DOCs) include coma, vegetative state, and the minimally conscious state.²⁴ The legal community is likely most familiar with what has been called the vegetative state, the medical condition at the heart of high-profile cases such as *Quinlan*,²⁵ *Cruzan*,²⁶ and *Schiavo*.²⁷ This Section will briefly define each of these DOCs to orient the reader to the subject matter of this

"Improvement Standard"? Coverage for Severe Brain Injury After *Jimmo v. Sebelius*, 44 J.L. MED. & ETHICS 182 (2016).

23 See, e.g., *Obergefell v. Hodges*, 135 S. Ct. 2584, 2589 ("The fundamental liberties protected by the Fourteenth Amendment's Due Process Clause extend to certain personal choices central to individual dignity and autonomy . . .").

24 Some readers may wonder whether the locked-in syndrome is also a disorder of consciousness. The locked-in syndrome differs from disorders of consciousness in that a person in such a state is awake and conscious but unable to move (i.e., paralyzed) or speak. Giacino et al., *supra* note 7, at 101 (describing how the locked-in syndrome compares with disorders of consciousness); Steven Laureys et al., *The Locked-In Syndrome: What Is It Like To Be Conscious but Paralyzed and Voiceless?*, 150 PROGRESS BRAIN RES. 495 (2005) (describing the locked-in syndrome).

25 *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

26 *Cruzan ex rel. Cruzan v. Mo. Dep't of Health*, 497 U.S. 261 (1990).

27 The last in a long line of cases is *Schiavo ex rel. Schlinder v. Schiavo*, 403 F.3d 1294 (11th Cir. 2005).

paper and update diagnostic classifications, which have refined the vegetative state category into distinct subcategories based on whether it is persistent or permanent. We will also introduce a new category, the minimally conscious state, which is often confused with the vegetative state.

1. Coma

“The defining clinical feature of coma is the complete loss of spontaneous or stimulus-induced arousal.”²⁸ A coma typically lasts a few weeks after a brain injury.²⁹ “After receiving an injury severe enough to cause a coma, a self-limited and eye-closed state of unresponsiveness, a patient may: recover; sustain whole brain death; or pass into the vegetative state.”³⁰

2. Vegetative State³¹

A vegetative state (VS) is one in which a person is unconscious, but seemingly “wakeful.”³² This means that a patient’s eyes may be open, but she lacks all other markers of consciousness, such as the ability to communicate or understand commands. Additionally, any movement she makes is purposeless, a result only of a functioning brain stem.³³ Jennett and Plum describe this state as wakeful unresponsiveness.³⁴ Such persons are “unaware of self or environment.”³⁵ If a patient is in a VS for more than thirty days, she is said to be in a persistent vegetative state.³⁶ If the VS is a result of anoxic brain injury³⁷ and

28 Giacino et al., *supra* note 7, at 100.

29 Joseph J. Fins, *Being Conscious of Their Burden: Severe Brain Injury and the Two Cultures Challenge*, 1157 ANN. N.Y. ACAD. SCI. 131, 135 (2009) [hereinafter Fins, *Conscious Burden*].

30 Joseph J. Fins, *Minds Apart: Severe Brain Injury, Citizenship, and Civil Rights*, in 13 LAW AND NEUROSCIENCE: CURRENT LEGAL ISSUES 367, 372 (Michael Freeman ed., 2010) [hereinafter Fins, *Minds Apart*].

31. The seminal paper on the vegetative state is Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 299 LANCET 734 (1972).

32 Fins, *Conscious Burden*, *supra* note 29, at 137; see Joseph J. Fins, *Lessons from the Injured Brain: A Bioethicist in the Vineyards of Neuroscience*, 18 CAMBRIDGE Q. HEALTHCARE ETHICS 7, 7 (2009) [hereinafter Fins, *Lessons*]; Joseph J. Fins, *Neuroethics, Neuroimaging, and Disorders of Consciousness: Promise or Peril*, 122 TRANSACTIONS AM. CLINICAL & CLIMATOLOGICAL ASS’N 336, 338 (2010) [hereinafter Fins, *Neuroethics*]; Giacino et al., *supra* note 7, at 100.

33 Joseph J. Fins, *Affirming the Right to Care, Preserving the Right to Die: Disorders of Consciousness and Neuroethics After Schiavo*, 4 PALLIATIVE & SUPPORTIVE CARE 169, 172 (2006) [hereinafter Fins, *Right to Care*]; Fins, *Lessons*, *supra* note 32, at 7; Fins, *Minds Apart*, *supra* note 30, at 368-69; Fins, *Neuroethics*, *supra* note 32, at 338; Giacino et al., *supra* note 7, at 100.

34 Jennett & Plum, *supra* note 31, at 734.

35 Multi-Soc’y Task Force on PVS, *Medical Aspects of the Persistent Vegetative State, Part I*, 330 NEW ENG. J. MED. 1499, 1500 (1994) [hereinafter Task Force]; see Fins, *Conscious Burden*, *supra* note 29, at 137; Fins, *Lessons*, *supra* note 32, at 7; Fins, *Neuroethics*, *supra* note 32, at 338.

36 Task Force, *supra* note 35, at 1501; see Fins, *Minds Apart*, *supra* note 30, at 372; Fins,

persists for more than three months, the patient is reclassified as being in a permanent vegetative state.³⁸ If the VS is a result of traumatic brain injury and persists for more than twelve months, the patient is likewise reclassified as being in a permanent vegetative state.³⁹ If properly diagnosed, there is no hope for recovery once a patient is classified as being in a permanent vegetative state.⁴⁰

3. Minimally Conscious State

A consensus statement on the minimally conscious state (MCS) was not articulated until relatively recently. The MCS became a formal diagnostic category in 2002.⁴¹ As the science of medical care for the injured brain advanced, it became possible for patients who previously might have died or ended up in a permanent vegetative state to recover consciousness to some degree.⁴² These advances included surgical interventions such as the use of intraventricular shunts and craniotomy used to treat closed head injuries, mitigating or preventing herniation or death.⁴³ With such interventions, patients can now have a different trajectory.

The MCS is distinct from a VS in that it “is a condition of severely altered consciousness characterized by minimal but definite behavioral evidence of self or environmental awareness.”⁴⁴ “Patients in the MCS have definitive evidence of consciousness, demonstrating intention, attention, memory, and awareness of the self, others, or the environment.”⁴⁵ A person can progress from a coma or not yet

Right to Care, *supra* note 33, at 173.

37 This occurs when the brain has been deprived of oxygen.

38 Fins, *Right to Care*, *supra* note 33, at 173; Fins, *Conscious Burden*, *supra* note 29, at 137; Fins, *Border Zones*, *supra* note 9, at 52; Fins, *Minds Apart*, *supra* note 30, at 372; Fins, *Neuroethics*, *supra* note 32, at 339; Giacino et al., *supra* note 7, at 100.

39 Fins, *Right To Care*, *supra* note 33, at 173; Fins, *Conscious Burden*, *supra* note 29, at 137; Fins, *Border Zones*, *supra* note 9, at 52; Fins, *Minds Apart*, *supra* note 30, at 372; Fins, *Neuroethics*, *supra* note 32, at 339; Giacino et al., *supra* note 7, at 100.

40 Fins, *Minds Apart*, *supra* note 30, at 372; Fins, *Neuroethics*, *supra* note 32, at 340. The condition is distinct from brain death, however, in that the brain stem is still intact and regulating bodily functions such as breathing. Fins, *Lessons*, *supra* note 32, at 7-8; Fins, *Neuroethics*, *supra* note 32, at 338. In brain death, “no brainstem functions are preserved and these patients do not exhibit spontaneous respiration when challenged with an apnea examination.” Fins, *Neuroethics*, *supra* note 32, at 337.

41 Giacino et al., *supra* note 6. Giacino first labeled this category the MCS in 1997, but the term was not accepted until 2002. Fins, *Lessons*, *supra* note 32, at 9; *see also* FINS, RIGHTS COME TO MIND, *supra* note 9, at 71-79 (describing Giacino’s involvement in developing the category of the MCS).

42 Bullock et al., *supra* note 3, at S2-1.

43 *Id.*

44 Giacino et al., *supra* note 7, at 100.

45 Fins, *Neuroethics*, *supra* note 32, at 340.

permanent VS to a MCS.⁴⁶ There is no definitive information about how many persons exist in a MCS.⁴⁷

The MCS is often difficult to diagnose because of “response inconsistency” in which at one point there may be evidence of “volitional behavior” but not at another.⁴⁸ Furthermore, some minimally conscious persons may not have any motor function, which makes diagnosis without neuroimaging difficult.⁴⁹ Improperly diagnosing the MCS as permanent VS, however, may mean termination of life support, improper medical care such as not providing pain medication,⁵⁰ not providing rehabilitation, and depriving such persons of community.⁵¹

Recovery of functions for persons in the MCS may take years or decades.⁵² Even with recovery, persons who had a DOC from a severe brain injury may be disabled for the remainder of their lives.⁵³

B. Importance of Rehabilitation for Persons in a Minimally Conscious State

Rehabilitation-oriented treatments for those with a DOC are meant to aid them in recovering “consciousness, communication, and functional competency.”⁵⁴ Some studies have shown that almost seventy percent of patients with traumatic brain injury who receive inpatient rehabilitation recover consciousness, and just over twenty percent are able to be functionally independent again.⁵⁵

⁴⁶ *Id.*; Giacino et al., *supra* note 7, at 100.

⁴⁷ See FINS, RIGHTS COME TO MIND, *supra* note 9, at 287; Joseph J. Fins et al., *Late Recovery from the Minimally Conscious State: Ethical and Policy Implications*, 68 NEUROLOGY 304, 306 (2007) [hereinafter Fins et al., *Late Recovery*]; Joseph J. Fins et al., *The Minimally Conscious State: A Diagnosis in Search of an Epidemiology*, 64 JAMA NEUROLOGY 1400 (2007) (calling for epidemiological studies on the MCS);

⁴⁸ Fins, *Neuroethics*, *supra* note 32, at 340 (“The challenge is that these behaviors are episodic and intermittent and not reproducible, making these patients indistinguishable from vegetative patients to the untrained eye, especially in an isolated single examination.”); Giacino et al., *supra* note 7, at 100, 103.

⁴⁹ FINS, RIGHTS COME TO MIND, *supra* note 9, at 300.

⁵⁰ Patients in a MCS have intact pain networks. Steven Laureys et al., *Cortical Processing of Noxious Somatosensory Stimuli in the Persistent Vegetative State*, 17 NEUROIMAGE 732 (2002).

⁵¹ Giacino et al., *supra* note 7, at 103.

⁵² Fins, *Conscious Burden*, *supra* note 29, at 137-38.

⁵³ FINS, RIGHTS COME TO MIND, *supra* note 9, at 113 (describing the variance in recovery from severe brain injury).

⁵⁴ Giacino et al., *supra* note 7, at 107.

⁵⁵ Risa Nakase-Richardson et al., *Longitudinal Outcome of Patients with Disordered Consciousness in the NIDRR TBI Model Systems Program*, 29 J. NEUROTRAUMA 59 (2012); see also FINS, RIGHTS COME TO MIND, *supra* note 9, at 288-89 (describing the Nakase-Richardson et al. study). These numbers are likely conservative estimates of the potential effect of rehabilitation on those with severe brain injury and subsequent DOCs.

One intervention that has been shown to be effective for patients in a VS or MCS is amantadine, a drug used to treat influenza. One large, randomized controlled study showed that amantadine could accelerate recovery from a VS.⁵⁶ Zolpidem, a sleep aid, is another pharmacological intervention that has also been demonstrated to be effective for a small minority of patients with a DOC.⁵⁷

There is also some evidence of effectiveness of non-pharmacological interventions. Neuroprosthetics may be used to aid in communication and recovery.⁵⁸ Neuroprosthetics include communication boards or other similar devices, deep brain stimulation (DBS), and neuroimaging.⁵⁹ Neuroimaging is functional magnetic resonance imaging (fMRI) scans and positron emission tomography (PET).⁶⁰ To assess whether a behaviorally nonresponsive patient is conscious or to communicate with a conscious patient who has no or limited motor function, scans are made of the patient while they are asked to think about performing different tasks to indicate either “yes” or “no” in response to questions.⁶¹ Also, a pilot study (or proof of principle study) of DBS of the central thalamus demonstrated behavioral improvements for one patient with a DOC.⁶²

56 Joseph T. Giacino et al., *Placebo-Controlled Trial of Amantadine for Severe Traumatic Brain Injury*, 366 NEW ENG. J. MED. 819 (2012) (demonstrating that recovery is accelerated for patients with DOC who are given amantadine relative to a placebo over a four-week period while receiving inpatient rehabilitation, and suggesting that future research focus on whether long-term outcomes are improved).

57 John Whyte & Robin Myers, *Incidence of Clinically Significant Responses to Zolpidem Among Patients with Disorders of Consciousness: A Preliminary Placebo Controlled Trial*, 88 AM. J. PHYSICAL MED. & REHAB. 410 (2009) (showing that one patient in the VS shifted to the MCS after receiving zolpidem, but this drug had no effect on the other 14 participants in the study).

58 Some have noted the high cost of neuroimaging and have argued that access to lower cost alternatives such as pharmacological agents to restore consciousness and communication may be more practical. See, e.g., FINS, RIGHTS COME TO MIND, *supra* note 9, at 301. Some organizations are creating low-cost, individually tailored devices that can aid those with brain injury to communicate. See, e.g., SPEAK YOUR MIND FOUNDATION, <http://speakyourmindfoundation.org> (last visited Oct. 10, 2015).

59 The founder of Speak Your Mind Foundation describes a customized, low-cost communication device, which consisted of a set of glasses, camera, and software that helped a young woman who had a brain stem stroke communicate. *Id.* The total cost of the device is \$30, and it enabled communication that would otherwise be impossible. *Id.* Similar devices on the market cost \$15,000. *Id.*

60 See Fins, *Neuroethics*, *supra* note 32, at 336.

61 See Fins, *Minds Apart*, *supra* note 30, at 376 (noting the “disturbing possibility of consciousness obscured by a physical incapacity to communicate and make one’s presence known”); see also Joseph J. Fins & Nicholas D. Schiff, *In the Blink of the Mind’s Eye*, 40 HASTINGS CTR. REP. 21, 21 (2010) (reporting how an fMRI could allow patients to communicate preferences while in a MCS).

62 See Nicholas D. Schiff et al., *Behavioural Improvements with Thalamic Stimulation After Severe Traumatic Brain Injury*, 488 NATURE 600, 601 (2007) (reporting on a study of one patient who regained some language capacity and the ability to swallow food).

Additionally, physical therapy may also be effective.⁶³

Most of these interventions are investigational,⁶⁴ but this does not mean that they should not be made available to patients in DOC through access to clinical trials.⁶⁵ Scientific research has demonstrated that drugs and devices can functionally augment consciousness and communication for these patients;⁶⁶ further translational research may lead to more progress and discovery.⁶⁷

While there may be spontaneous recovery from a coma or VS to a MCS, it is important that those with a DOC receive available rehabilitation-oriented treatments. Rehabilitation will aid in accurately assessing a patient's diagnostic state, which will then aid with prognosis. Using rehabilitative techniques may prevent premature withdrawal of life support from those who are conscious or have the potential to be conscious.⁶⁸ Additionally, rehabilitation may lead patients to be able to convey whether they are experiencing pain, which will then lead to better medical treatment.⁶⁹ Perhaps most importantly, rehabilitation may make it possible for patients with a DOC to communicate with their family members.

C. Persons in a Minimally Conscious State Often Lack Access to Rehabilitation

Patients who have a DOC often lack access to rehabilitation that could aid them in recovering consciousness and functional abilities. There are several reasons for this lack of access. One reason is the high rate of misdiagnosis of the

63 Linda E. Mackay et al., *Early Intervention in Severe Brain Injury: Long-Term Benefits of a Formalized Program*, 73 ARCHIVES PHYSICAL MED. & REHAB. 635 (1992).

64 Some are not experimental per se, but rather are off-label uses of prescription drugs.

65 FINS, RIGHTS COME TO MIND, *supra* note 9, at 295.

66 See, e.g., Giacino et al., *supra* note 7 (summarizing the state of scientific research).

67 *Id.* But see Joseph J. Fins & Barbara Pohl, *Guardianship and the Injured Brain: Representation and the Rights of Patients and Families*, in FINDING CONSCIOUSNESS (Sinnott-Armstrong, ed.) (2016) (discussing how guardianship may be problematic for persons with DOC); Megan S. Wright et al., *Guardianship and Clinical Research Participation: The Case of Wards with Disorders of Consciousness*, 27 KENNEDY INST. ETHICS J. (forthcoming 2016) (discussing how guardianship for this population may impede access to research or experimental interventions that may aid those with DOCs, and recommending that state guardianship laws permit guardians to consent on behalf of their wards to such research or interventions).

68 Professor Fins has repeatedly written about patients who are presumed “hopeless” but in fact are conscious or have the capacity to regain consciousness. See, e.g., FINS, RIGHTS COME TO MIND, *supra* note 9, at 98 (describing the erroneous presumption that a patient was “hopeless” and vegetative when in fact she was in a MCS); Fins, *Right to Care*, *supra* note 33, at 174 (noting that mistaken assumptions about patients in a MCS can “erroneously support decisions to prematurely withhold and/or withdraw life-sustaining therapy before the patient has had time to declare him or herself prognostically”); see also Fins et al., *Late Recovery*, *supra* note 47, at 306 (arguing that decisions about life-sustaining for patients with DOC be fully and scientifically informed).

69 *Id.* at 301 (describing how patients in MCS may be in pain, but unable to communicate it); Giacino et al., *supra* note 7, at 9 (describing how those in MCS should have pain treated because they can subjectively experience pain unlike those in VS).

MCS. Some studies cite a misdiagnosis rate of approximately 30-40%.⁷⁰ The rate of misdiagnosis is high, in part, because of the intermittent consciousness a patient in MCS experiences,⁷¹ and because without proper neuropsychiatric testing, it may be impossible to recognize or elicit behavioral manifestations of consciousness.⁷² It is also due to the recentness of the diagnostic category and lack of knowledge in the broader medical community about this condition.⁷³ It is also because

patients with disorders of consciousness may need a longer period of time to declare themselves than other critically ill patients in the acute care setting. In a setting where decisional constructs operate in days and weeks, and not months, it becomes too easy to mistake the failure to improve quickly as an indication that no improvement will be possible at all.⁷⁴

If patients are incorrectly assessed as being in a permanent VS rather than MCS, they will not receive rehabilitation because those in a permanent VS by definition cannot recover.⁷⁵

Another reason that patients with DOC lack access to rehabilitation is what has been referred to as the “culture of nihilism” surrounding severe brain injury.⁷⁶ Given that patients with severe brain injury and subsequent DOC may be viewed as hopeless by health care professionals and society at large, perhaps in part due

⁷⁰ Caroline Schnakers et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9 BMC NEUROLOGY 35 (2009).

⁷¹ Fins, *Neuroethics*, *supra* note 32, at 340-41 (“The behaviors that patients manifest in consciousness are episodic and intermittent but definite. They are not captured in a single examination, and if a family sees a behavior and only reports it to a nursing home staff, the staff are likely to discount the observation, chalking it up to denial, especially when the patient has come from an academic medical center in which the patient was definitely diagnosed as being vegetative.”).

⁷² Some patients may not have motor function. See FINS, RIGHTS COME TO MIND, *supra* note 9, at 300; Fins, *Neuroethics*, *supra* note 32, at 343 (summarizing a study wherein patients who were thought to be vegetative were shown to be minimally conscious after being able to use yes/no communication through neuroimaging); Joseph T. Giacino et al., *The JFK Coma Recovery Scale-Revised: Measurement Characteristics and Diagnostic Utility*, 85 ARCHIVES PHYSICAL MED. & REHAB. 2020 (2004) (describing how the revised coma recovery scale was able to identify persons as being in a minimally conscious state who were formally diagnosed as being in a persistent vegetative state).

⁷³ Fins, *Conscious Burden*, *supra* note 29, at 137 (referring to a “knowledge deficit” of physicians about the MCS).

⁷⁴ Fins, *Right to Care*, *supra* note 33, at 173-74.

⁷⁵ Fins, *Neuroethics*, *supra* note 32, at 340.

⁷⁶ FINS, RIGHTS COME TO MIND, *supra* note 9, at 82; Fins, *Conscious Burden*, *supra* note 29, at 134-36; Fins, *Lessons*, *supra* note 32, at 7.

to highly publicized right-to-die cases such as *Quinlan*, *Cruzan*, and *Schiavo*, patients in a VS or MCS with potential to recover may not have this potential recognized.⁷⁷ This is especially unfortunate given that as many as half of those with DOC recover to some degree over time.⁷⁸

A final reason that patients with DOC lack access to rehabilitation concerns inpatient rehabilitation admission criteria and health care insurance funding constraints. In the United States, admission to inpatient rehabilitation depends on meeting standards inapplicable to those with DOC. For example, admission or reimbursement standards may require that a patient already be in a MCS upon discharge from a hospital, or may require “medical necessity” or use an “improvement standard.”⁷⁹ Few patients with severe brain injury and subsequent DOC can meet these criteria upon release from the hospital, but if given rehabilitation could recover to the state that is deemed necessary for them to have access to rehabilitation in the first place.⁸⁰

D. Consequences of Lack of Access to Rehabilitation for Persons in a Minimally Conscious State

What happens to patients in a MCS who lack access to rehabilitation that could help them recover? If patients are in a MCS upon discharge from the hospital following medical interventions allowing patients to survive their brain injury, they are sent to inpatient rehabilitation facilities. Patients in a VS,

⁷⁷ See FINS, RIGHTS COME TO MIND, *supra* note 9, at 82; Fins, *Minds Apart*, *supra* note 30, at 368-71; Fins, *Conscious Burden*, *supra* note 29, at 133, 134-36; see also Joseph J. Fins, *Constructing an Ethical Stereotaxy for Severe Brain Injury: Balancing Risks, Benefits, and Access*, 4 NATURE REV. NEUROSCIENCE 323 (2003) (linking the right to die movement and brain injury); Fins, *Minds Apart*, *supra* note 30, at 367 (“Although *Quinlan* was laudable for enfranchising patients and families with a right to die, the case’s legacy has also had the unintended consequence of marginalizing a whole class of patients with disorders of brain injury, presumed to be beyond any hope of recovery and thus undeserving of care.”); Giacino et al., *supra* note 7, at 108-09.

⁷⁸ See Nakase-Richardson et al., *supra* note 55; Giacino et al., *supra* note 7, at 108-109 (describing the ethical implications of the Nakase-Richardson et al. study findings).

⁷⁹ Giacino et al., *supra* note 7, at 109. Many scholars have critiqued medical necessity. See, e.g., FINS, RIGHTS COME TO MIND, *supra* note 9, at 300; Fins, *Conscious Burden*, *supra* note 29, at 132; Fins, *Right to Care*, *supra* note 33, at 174; Fins et al., *supra* note 22. As Professor Fins has noted,

Long before a patient shows signs of improving behaviorally, his brain may demonstrate changes that herald recovery. But medical necessity is a construct that presupposes motor function, a kind of ability that would discriminate against those who cannot move, who cannot respond to a command because they cannot control their limbs. For some minimally conscious patients, the failure to properly assess their minds could lead to the assumption that they were not conscious, when their nonresponse was due to lack of motor function.

FINS, RIGHTS COME TO MIND, *supra* note 9, at 300.

⁸⁰ See Giacino et al., *supra* note 7, at 109.

however, are often discharged from hospitals to nursing homes or other chronic/custodial care facilities.⁸¹ While in nursing homes or other chronic care facilities, they are often not given the rehabilitation that might speed up their potential recovery. Importantly, a patient in a VS could transition into a MCS, but is then lost due to lack of follow up and improper diagnosis. There are two failures in this process: failure to receive rehabilitation, and if there is rehabilitation, it is often too truncated to be as effective as possible.⁸²

The current infrastructure does not allow for patients in a MCS to realize their potential, which may require more precise diagnosis and necessitate specialized treatment. Not all such patients will emerge beyond this state, but their potential for recovery is not realized when they lack access to services that could help them. Furthermore, any signs of their recovery of consciousness, given that their consciousness is intermittent, may be missed given that nursing home staff is not seeking such indications.⁸³ Patients are often surrounded by persons who are elderly⁸⁴ and actively dying, also further conflating their status

81 See FINS, RIGHTS COME TO MIND, *supra* note 9, at 290; Giacino et al., *supra* note 7, at 109. Additionally, families may be encouraged to withhold or withdraw care from the brain-injured person or to donate the patient's organs. Needless to say, if the patient is minimally conscious or has the possibility to become so, such a decision is premature. See FINS, RIGHTS COME TO MIND, *supra* note 9, at 290; Fins, *Right to Care*, *supra* note 33, at 174 (explaining that families may "erroneously support decisions to prematurely withhold and/or withdraw life-sustaining therapy before the patient has had time to declare him or herself prognostically"); Fins, *Conscious Burden*, *supra* note 29, at 134-36.

82 John Whyte & Risa Nakase-Richardson, *Disorders of Consciousness: Outcomes, Comorbidities, and Care Needs*, 94 ARCHIVES PHYSICAL MED. & REHAB. 1851 (2013) (summarizing the state of clinical research on DOC, and asserting that late-term recovery from a DOC is not uncommon and that access to inpatient rehabilitation, which may be helpful, is problematic given healthcare policies).

83 FINS, RIGHTS COME TO MIND, *supra* note 9, at 82; Fins, *Conscious Burden*, *supra* note 29, at 138 ("Sometimes these episodic and early flashes of awareness go unnoticed or unappreciated by staff only to be the harbinger later of more robust recovery of communication function."); Giacino et al., *supra* note 7, at 109. As Professor Fins has described elsewhere,

There are additional challenges to diagnostic accuracy because of when the transition from VS to MCS occurs and where it takes place. At that juncture in their recovery, patients will likely have been transferred to chronic or long-term care and be in a setting of lesser medical acuity than the acute care hospital where definitive medical and surgical care was rendered. Because of the relative prestige and standing of these centers, physicians in chronic care may be hesitant to question the discharge diagnosis, even though a diagnostic revision would only reflect the ongoing biology of recovery and not represent an assessment error upstream in the provision of care.

Fins, *Minds Apart*, *supra* note 30, at 373; see also Fins, *Right to Care*, *supra* note 33, at 174 (reporting that acute-care practitioners may not appreciate upon discharge the potential for their patients to improve over time).

84 FINS, RIGHTS COME TO MIND, *supra* note 9, at 308; Fins, *Minds Apart*, *supra* note 30, at 382

with people at the end of life. This may be a distressing experience for these recovering patients who may not be able to communicate their distress.⁸⁵

Finally, these profoundly disabled persons are isolated and segregated from other conscious persons and from “mainstream medical care.”⁸⁶ If their consciousness were recognized, perhaps through wider use of the scientifically validated Coma Recovery Scale-Revised (CRS-R) by skilled examiners,⁸⁷ then patients in a MCS could be more fully integrated into society, which is a not only a desirable social goal, but also legally compelled.⁸⁸ Significantly, persons with MCS are denied full access to interpersonal relationships when they are not given the tools to help them communicate.⁸⁹ This leads to segregation, or what some have termed “neuronal segregation,”⁹⁰ which can cause both MCS patients and their families to suffer.

E. How the Injured Brain Is Similar to the Developing Brain

Recent scientific research has demonstrated that the injured brain is resilient and has the potential to recover to some degree after sustaining trauma.⁹¹ As Professor Fins has noted in a recent book, there is a

developmental capacity of injured brains to recover and regain ground, if properly assisted. Education for the young and rehabilitation for the brain injured are more closely linked if recovery from brain injury is viewed in a developmental frame. That is, an unfolding process that occurs as a process of an evolving biology from a new set point determined by the patient’s injury.⁹²

(describing how patients with DOC with the potential to recover are surrounded by those in active decline in nursing homes).

85 FINS, RIGHTS COME TO MIND, *supra* note 9, at 308.

86 *Id.* at 291, 298.

87 Giacino et al., *supra* note 72 (describing how the revised coma recovery scale can distinguish the MCS from the VS).

88 See American with Disabilities Act, 42 U.S.C. § 12101 (2012); *see also* G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities, art. 26 (Jan. 24, 2007) (emphasizing the rights of disabled individuals to be integrated into society through rehabilitative services); FINS, RIGHTS COME TO MIND, *supra* note 9, at 294 (“If individuals who might be able to communicate are denied the resources to do so, they are then denied access to being maximally integrated into society.”).

89 FINS, RIGHTS COME TO MIND, *supra* note 9, at 299.

90 *Id.* at 290-91.

91 Henning U. Voss et al., *Possible Axonal Regrowth in Late Recovery from the Minimally Conscious State*, 116 J. CLINICAL INVESTIGATION 2005 (2006).

92 FINS, RIGHTS COME TO MIND, *supra* note 9, at 306.

In both the young developing brain and in the injured recovering brain, there is new axonal growth (connections between neurons).⁹³ Both the young brain and the injured brain appear to share a common mechanism of axonal sprouting: the first as a developmental process, and the second as a regenerative one with new axonal connections between remaining neurons.⁹⁴

Education assists in the developmental process, and rehabilitation assists in the healing process.⁹⁵ In fact, those with brain injury often speak of their recovery in terms of “re-learning,” which supports the link between education of the developing brain and rehabilitation of the injured brain.⁹⁶ It may be instructive to think of rehabilitation of the injured brain as an educational intervention as much as a medical intervention. As Professor Fins has described elsewhere:

Both childhood education and brain injury rehabilitation are linked to developmental processes. Education is coupled with the progressively maturing brain, with curricula geared to what is cognitively and socially possible for young and developing minds. Brain-injury rehabilitation can be also understood as hinging upon a recuperative process that often retraces earlier developmental milestones. This recapitulation of an earlier process is made necessary by the setback of injury. Like the education of a child, brain injury rehabilitation’s purpose is to help an individual meet the progressive functional goals and to maximize one’s potential. If this premise is accepted, then rehabilitation is as important to the injured citizen as school is to the young child. In a Rawlsian frame, then, each provides the individual with the capabilities to maximize their participation in a shared democratic life.⁹⁷

Research findings from contemporary neuroscience supports this analogy.⁹⁸

93 *Id.*; Fins, *Lessons*, *supra* note 32, at 10; Randolph J. Nudo, *Recovery After Brain Injury: Mechanisms and Principles*, 7 *FRONTIERS HUM. NEUROSCIENCE* 887 (2013) (reviewing the literature on neuroplasticity).

94 *See* Nudo, *supra* note 93; Voss et al., *supra* note 91.

95 *See* FINS, *RIGHTS COME TO MIND*, *supra* note 9, at 306-07 (“Like the education of a child, brain injury rehabilitation’s purpose is to help an individual meet progressive functional goals and to maximize one’s potential . . .”).

96 *Id.*

97 Fins, *Minds Apart*, *supra* note 30, at 381.

98 Nudo, *supra* note 93, at 11 (“As a result of the abundance of evidence that has demonstrated that the brain is plastic after neuronal injury, and that behavioral experience can alter

As noted in a recent review article of neuroplasticity research, “Clues to understanding plasticity in adult brains can be found throughout the developmental neuroscience literature Though long-range axonal sprouting was once thought to be non-existent in adult animals, injury creates a particularly ripe environment for axonal sprouting processes to be re-initiated.”⁹⁹

Many persons could benefit from rehabilitation and other medical interventions. We confine our analogy of rehabilitation and education to medical conditions in which there is potential for the brain to heal in response to repeated “learning” exercises, which is similar to how a brain develops early in the life course in response to educational interventions. That is, persons with brain injury and subsequent DOCs are distinct in this way compared to someone with arthritis who may need access to drugs or physical therapy to treat their condition. The regenerative process that occurs in response to rehabilitation of the injured brain recapitulates the earlier developmental script, which is why the analogy to education early in the life course is especially apt.

II. IMPERATIVE TO PROVIDE REHABILITATION TO THE INJURED BRAIN

In this Part, we argue that it is ethically and legally imperative to provide rehabilitative technologies to patients with DOC. There are two bases for this assertion. Beyond respect for personhood, there is an ethical imperative to provide rehabilitation to the injured brain by analogy to the legally created expectation that children will be provided with free public education. Second, there is a statutory right to rehabilitation of the injured brain under the Americans with Disabilities Act and case law interpreting this Act. We conclude this Part by addressing objections to our arguments.

A. By Analogy to Expectation of Access to Free Public Education

1. Expectation of Access to Free Public Education

Education is a fundamental right in many countries, written into their constitutional text.¹⁰⁰ Education is also recognized as a right in international legal

neuronal structure and function in both healthy and injured brains, it is now clear that principles of neuroplasticity can form the foundation for a wide range of therapeutic approaches to recovery.”).

⁹⁹ *Id.*

¹⁰⁰ See Stephen Lurie, *Why Doesn't the Constitution Guarantee the Right to Education?*, ATLANTIC (Oct. 16, 2013), <http://www.theatlantic.com/education/archive/2013/10/why-doesnt-the-constitution-guarantee-the-right-to-education/280583> (describing how the United States is relatively unique in not guaranteeing such a constitutional right); see also Bert B. Lockwood et al., *Litigating State Constitutional Rights to Happiness and Safety: A Strategy for Ensuring the Provision of Basic Needs to the Poor*, 2 WM. & MARY BILL RTS. J. 1, 16, 23 (1993) (noting that

documents such as the International Covenant on Economic, Social and Cultural Rights (ICESCR), which the United States has not ratified.¹⁰¹ According to ICESCR, the reason that education is a fundamental human right is because education can aid in human development, dignity, respect for liberty, and participation in society.¹⁰² The text avers that the state-parties to the ICESCR

agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance, and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.¹⁰³

Whether education is a federal constitutional right in the United States has been litigated, and the Supreme Court answered in the negative in *San Antonio Independent School District v. Rodriguez*.¹⁰⁴ In this equal protection case about how public schools were financed in Texas, the Court stated:

Education, of course, is not among the rights afforded explicit protection under our Federal Constitution. Nor do we find any basis for saying it is implicitly so protected. As we have said, the undisputed importance of education will not, alone, cause this Court to depart from the usual standard for reviewing a State's social and economic legislation.¹⁰⁵

while the U.S. Constitution does not mention education explicitly, FDR's "Second Bill of Rights" included a right to education).

¹⁰¹ International Covenant on Economic, Social and Cultural Rights, *adopted* Dec. 16, 1996, 993 U.N.T.S. 3 (entered into force Jan. 3, 1976). While not binding on U.S. Courts, such documents may be used to help interpret the U.S. Constitution. *See, e.g.*, Susan H. Bitensky, *Theoretical Foundations for a Right to Education Under the U.S. Constitution: A Beginning to the End of the National Education Crisis*, 86 NW. U. L. REV. 550, 616-22 (1991). As Professor Bitensky notes, "The positive right to education as an international human rights norm has the potential to breathe a more complete and rational meaning into the language of these constitutional provisions." *Id.* at 622.

¹⁰² International Covenant on Economic, Social and Cultural Rights at 13.1.

¹⁰³ *Id.*

¹⁰⁴ 411 U.S. 1 (1973).

¹⁰⁵ *Id.* at 35.

Thus, the United States is unique among developed nations in not recognizing an affirmative constitutional right to education.¹⁰⁶

In response, many legal scholars assert that there is such a right.¹⁰⁷ Recent scholarship asserting that there is a positive constitutional right to education has argued that the right comes from substantive due process doctrine.¹⁰⁸ The Due Process clause of the Fourteenth Amendment has been the source of many

106 Lurie, *supra* note 100 (arguing that one of the reasons that the United States does not rank well in terms of education systems relative to other countries is because there is not a constitutional commitment to education and calling for a constitutional amendment, which he asserts will increase the cultural value placed on education, help improve U.S. education, and make America more globally competitive).

107 See, e.g., Bitensky, *supra* note 101 (identifying every possible source in the U.S. Constitution for a right to education, and asserting that none of the explicit rights have any meaning without education); Barry Friedman & Sara Solow, *The Federal Right to an Adequate Education*, 81 GEO. WASH. L. REV. 92 (2013); Daniel S. Greenspahn, *A Constitutional Right To Learn: The Uncertain Allure of Making a Federal Case out of Education*, 59 S.C. L. REV. 755 (2008); Areto A. Imoukhuede, *Education Rights and the New Due Process*, 47 IND. L. REV. 467 (2014); Edward Rubin, *The Affordable Care Act, the Constitutional Meaning of Statutes, and the Emerging Doctrine of Positive Constitutional Rights*, 53 WM. & MARY L. REV. 1639, 1715 (2012).

108 See, e.g., Friedman & Solow, *supra* note 107, at 96 (arguing that there is a right to “minimally adequate” public education under Due Process Clause); Greenspahn, *supra* note 107, at 773 (arguing that the 14th Amendment is the best source of such a right); Imoukhuede, *supra* note 107, at 470, 478, 491-92 (arguing that a right to education should be grounded in liberty-based arguments that emphasize dignity and the connection of dignity to education, rather than equality-based arguments that the court has been distancing itself from). Professor Bitensky also leads her analysis of a right to education under the Due Process Clause. Bitensky, *supra* note 101, at 579-96.

The Due Process Clause is especially important given that equal protection-based constitutional claims are difficult to win. Asserting an equal protection claim is unlikely to be successful in regards to education. See Imoukhuede, *supra* note 107, at 491-92.

Equal protection-based claims are also especially difficult to prevail with when they pertain to persons with disabilities who do not get special protections in the form of heightened scrutiny. Kenji Yoshino, *The New Equal Protection*, 124 HARV. L. REV. 747, 748, 758-59 (2011). Because persons with disabilities do not get heightened scrutiny, state action that treats them differently is more likely to be upheld. *Id.* at 755-56, 760. Professor Yoshino argues that equality claims are now brought under the Due Process Clause as “dignity” claims. *Id.* at 748-50. He argues that this legal trend can be considered a positive development because the government can respond to an equality-based claim by “leveling-down,” whereas they cannot with a liberty-based claim. *Id.* at 787. Some Supreme Court Justices dislike constitutional dignity claims, however. See, e.g., *Obergefell v. Hodges*, 135 S. Ct. 2584, 2639 (Thomas, J., dissenting) (“[T]he Constitution contains no ‘dignity’ Clause, and even if it did, the government would be incapable of bestowing dignity. Human dignity has long been understood in this country to be innate.”).

The Supreme Court has recently noted the connection between due process and equal protection. See, e.g., *Obergefell*, 135 S. Ct., at 2590 (“The Due Process Clause and the Equal Protection Clause are connected in a profound way. Rights implicit in liberty and rights secured by equal protection may rest on different precepts and are not always coextensive, yet each may be instructive as to the meaning and reach of the other.”). But see *Obergefell*, 135 S. Ct., at 2623 (Roberts, C.J., dissenting) (“Absent from this portion of the opinion, however, is anything resembling our usual framework for deciding equal protection cases.”).

unenumerated constitutional rights, such as the right to privacy.¹⁰⁹ One standard test for whether something is an implied or unenumerated liberty-based right is whether the right is grounded in history and tradition.¹¹⁰ Using this commonsense test, scholars assert that there is an established constitutional right to education because of the long history of compulsory education of children and adolescents, as well as the federal government's historical involvement in granting lands for public schools.¹¹¹

Regardless of what legal scholars assert or the presence of compulsory education across the nation, however, *Rodriguez* still stands, and the Supreme Court has not recognized a positive constitutional right to education. Instead, the Court has explicitly recognized only a negative right to education—that is, a right to be free from governmental interference in educational choices.¹¹² The Court hinted in *Rodriguez* that there might be some minimum level of education that is constitutionally protected, however, which leaves open the possibility of an eventual positive expansion of this right to one that is constitutionally sanctioned

109 See Friedman & Solow, *supra* note 107, at 107 (describing how judges agree that unenumerated rights exist). Substantive due process doctrine actually began in education-related cases. *Id.* at 119-20.

110 See, e.g., *Washington v. Glucksburg*, 521 U.S. 702, 720-21 (1997) (holding a fundamental right may exist if it is “objectively, deeply rooted in this Nation’s history and tradition” and “implicit in the concept of ordered liberty, such that neither liberty nor justice would exist if they were sacrificed”). More “liberal” Justices also look to evolving understandings of what constitutes a fundamental right. Friedman & Solow, *supra* note 107, at 108.

In the recent context of whether same-sex marriage is a fundamental right under the Due Process Clause, the *Obergefell* Court wrote of the substantive due process test:

Courts must exercise reasoned judgment in identifying interests of the persons so fundamental that the State must accord them its respect. History and tradition guide and discipline the inquiry but do not set its outer boundaries. When new insight reveals discord between the Constitution’s central protections and a received legal stricture, a claim to liberty must be addressed.

Obergefell, 135 S. Ct. at 2589. This new test was critiqued by Chief Justice Roberts, who dissented from this opinion:

Allowing unelected federal judges to select which unenumerated rights rank as “fundamental”—and to strike down state laws on the basis of that determination—raises obvious concerns about the judicial role. Our precedents have accordingly insisted that judges “exercise the utmost care” in identifying implied fundamental rights, “lest the liberty protected by the Due Process Clause be subtly transformed into the policy preferences of the Members of this Court.”

Id. at 2616 (Roberts, C.J., dissenting) (internal citations omitted).

111 Bitensky, *supra* note 101, at 586-90; Friedman & Solow, *supra* note 107, at 114-16, 127.

112 See Bitensky, *supra* note 101, at 563-64, 573, 580-81 (discussing early Supreme Court cases establishing this negative right).

and supported.¹¹³ The *Rodriguez* Court also opined on the importance of education, noting that

[c]ompulsory school attendance laws and the great expenditures for education both demonstrate our recognition of the importance of education to our democratic society. It is required in the performance of our most basic public responsibilities, even service in the armed forces. It is the very foundation of good citizenship. Today it is a principal instrument in awakening the child to cultural values, in preparing him for later professional training, and in helping him to adjust normally to his environment. In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education.¹¹⁴

While the Court framed the importance of education initially in terms of participation in democratic society, a view echoed by others,¹¹⁵ the Court also recognized other functions of education. For example, the Court noted the connection between education and employment, normal socialization, adjustment to one's environment, and success in life. It is these latter functions of education that are significant to our argument.

While there is no federal constitutional right to education, access to free public education is, at the very least, an expectation. This is especially so because there is a right to education at the state and local level.¹¹⁶ In most states, this right

113 *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1, 36 (1973) (refusing to concede that "some identifiable quantum of education is a constitutionally protected" right). Several legal scholars have also discussed this possibility. Bitensky, *supra* note 101, at 566-67, 573; Friedman & Solow, *supra* note 107, at 117-19; Greenspahn, *supra* note 107, at 769-72. Greenspahn in particular notes that the language leaves open this possibility and discusses how the purposes for refusing to find such a right in the *Rodriguez* case are no longer applicable, but he ultimately argues that it is unlikely a court would find such a right given that they are "de-constitutionalizing" schools. Greenspahn, *supra* note 107, at 775-79. Professor Bitensky also notes that in other cases, the Supreme Court describes education not as a right, but also not "merely some governmental 'benefit' indistinguishable from other forms of social welfare legislation." Bitensky, *supra* note 101, at 568.

114 *Rodriguez*, 411 U.S. at 29-30 (quoting *Brown v. Board of Education*, 347 U.S. 483, 493 (1954)).

115 See, e.g., Bitensky, *supra* note 101, at 596-606 (describing the connection between participation in democracy and education).

116 Imoukhuede, *supra* note 107, at 492; James E. Ryan, *A Constitutional Right to Preschool?*, 94 CAL. L. REV. 49 (2006). Note that there is federal financing for and federal legislation about education, so there is a mixed federal-state system of and right to public education. See Friedman & Solow, *supra* note 107, at 142-43, 146-47 (describing how No Child Left Behind provides some funding for education, and federal spending on education has increased

is referenced in the state constitution.¹¹⁷ Additionally, every single state has set up a free public education system for children and adolescents, supported by local and state taxes, and compels attendance.¹¹⁸ Through litigation at the state level over the past several decades, the right to education has been defined as a right to “minimally adequate” rather than “equal” education.¹¹⁹

Given the legally created expectation of free public education for children and adolescents, along with a longstanding history of the provision of such education, there is an ethical obligation—if not a constitutional duty—to continue providing such education in order to meet citizens’ expectations. Indeed, this ethical obligation is particularly pronounced because education is so important for a functioning democratic society, as noted by the *Rodriguez* Court.¹²⁰

2. Rehabilitation of an Injured Brain Is Similar to Education of a Developing Brain

As discussed above,¹²¹ the rehabilitation of the injured brain is similar in many respects to the education of the developing brain. Just as the “first few years of life are crucial for cognitive development,”¹²² and early childhood education aids in this development, so is timely and consistent rehabilitation of the injured brain necessary for healing and “redevelopment” of the brain and restoration of brain function.

There is also reason to believe that the bipartisan political support for preschool would also exist for brain-injured persons with DOCs.¹²³ People

over time); Greenspahn, *supra* note 107, at 781-82 (describing how the majority of funding for education comes from the local and state level).

117 Friedman & Solow, *supra* note 107, at 116-17; Greenspahn, *supra* note 107, at 779-80; Ryan, *supra* note 116, at 53, 69 (noting that all state constitutions reference education in some way, but excepting seven states, all are silent as to the age at which public education is required).

118 Greenspahn, *supra* note 107, at 774, 781-82 (noting that school attendance is compulsory and noting that the source of funding for education is primarily states and municipalities).

119 After the *Rodriguez* decision, advocates for educational reform began bringing equal protection lawsuits at the state level, under the state constitutions. They had mixed success, losing more often than they won. They then started demanding “adequate” rather than “equal” education, and were much more successful. See Friedman & Solow, *supra* note 107, at 127-32; Greenspahn, *supra* note 107; Ryan, *supra* note 116, at 74.

120 *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1 (1973).

121 See discussion *supra* Section I.E.

122 Ryan, *supra* note 116, at 50 (arguing that this is, in part, why people widely support preschool).

123 *Id.* at 51 (“[T]he beneficiaries are a sympathetic and appealing group. One can hardly blame these young children for their own circumstances. They are as innocent and untainted as any group can be. Assisting children at this stage in their lives, to get them ‘on the right path,’ is an

support preschool so that children can have equality of opportunity, and because preschoolers need someone to provide them with education and care.¹²⁴ Similarly, brain-injured persons need provision of education and care. Both preschool and rehabilitation post-brain-injury are pivotal developmental periods.

3. If Understood as Education, Minimally Adequate Rehabilitation of Injured Brain Is Ethically Compelled

Given that rehabilitation of an injured brain can be thought of as similar to education of the developing brain, and given that there is a legally created expectation that the state will provide children, whose brains are developing, with education, we argue that rehabilitation of the injured brain should also be provided. Given the content of the state-level right to education is, at a minimum, the right to an “adequate” education, brain-injured persons with disorders of consciousness should receive “adequate” rehabilitation. This means that instead of being isolated in custodial care facilities, these patients should be given access to quasi-educational interventions that may aid them in realizing their post-injury potential. We recognize that this is a novel argument, and there is likely to be resistance to our assertions. Whatever one’s perspective, however, it is difficult to disagree with the premise that it is time to engage in a dialogue, accommodating ethical and legal challenges prompted by advances in neuroscience in diagnosis and treatment of DOCs.

Some may argue that because the legal expectation that persons will be provided with education is only extended to children aged five or six to around age eighteen, and not to adults,¹²⁵ our analogy is flawed because we are arguing for rehabilitation of injured *adult* brains. If, however, this expectation of education is conceived not based on chronology, but instead based on potentiality, our analogy survives. That is, if the purpose of education is not to educate children and adolescents, but instead the purpose of education is educate developing brains, which need education to reach their potential, then it makes

inherently attractive idea . . .”).

¹²⁴ *Id.* People also support education for persons with disabilities, also because of a strong belief in equality of opportunity. This principle is embodied in the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§ 1400-82 (2012). The IDEA promotes integrated education to the extent possible. Integration of persons with disabilities is important because segregation causes feelings of inferiority, as noted by the *Brown v. Board of Education*, 347 U.S. 483, 494 (1954) (“To separate [students] . . . because of their race generates a feeling of inferiority as to their status in the community that may affect their hearts and mind in a way unlikely to ever be undone.”).

¹²⁵ This right has not been extended to preschool or college. Some have argued that there should be a constitutional right to preschool, but have stopped short of arguing for such a right to college. *See* Ryan, *supra* note 116, at 88-90.

sense that there should be an expectation of re-education of an injured brain, which has potential to more fully develop. *We do believe that the purpose of legally mandated free public education of children is based on potentiality rather than chronology*, and therefore assert that our analogy between education of developing brains and rehabilitation of an injured brain is proper. That is, persons with brain injury have a period post-injury in which they go through a developmental process similar to that of early life, which is why we advocate for rehabilitative resources during this window of opportunity.

Some may also argue that the primary purpose of free public education of children is to prepare them to participate in democratic society, and that given the uncertainty about persons with a DOC or in a MCS being able, in the future, to exercise their rights to free speech or to vote, the rationale for asserting there should be access to rehabilitation for an injured brain based on the legal expectation of access to a free public education is not applicable. To this criticism of our argument, we respond by pointing to the IDEA,¹²⁶ which applies to persons who may never fully participate in democracy.

The IDEA strives to ensure that children with disabilities are provided access to a free public education, tailored to their individual circumstances, regardless of their disability and independent of their capacity to fully participate as citizens.¹²⁷ In the “Findings” section of the IDEA, Congress states:

Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

Notably, while participation in society is mentioned as one reason for the policy of educating children with disabilities, so are reasons such as living independently and having equal opportunity. Even children who may never be able to fully participate in democratic society are guaranteed an education because of the importance of education for community participation and integration.¹²⁸

Similar to children with profound intellectual disabilities who may never be able to fully participate in democratic society, persons in a MCS may likewise

126 Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-82 (2012).

127 *Id.* § 1400(d)(1)(A) (“The purposes of this title are to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living.”); *see also* FINS, RIGHTS COME TO MIND, *supra* note 9, at 307-08 (discussing the IDEA in the context of brain injury).

128 The IDEA provides for transition services to focus on outcomes such as community participation. *See id.* § 1401(34)(A).

not be able to fully participate. This possibility does not mean, however, that persons in a MCS should not be given rehabilitation, which may have other benefits, such as enhancing communication abilities, thus making it possible for them to be more integrated in society. Therefore, we assert that even given the uncertainty about the ability of persons in a MCS to fully participate in democratic society, there should be a recognized expectation to rehabilitation of the injured brain, a direct consequence of the nation's commitment to educating all persons and allowing them to develop to their full potential.

Given past and existing political support for preschool¹²⁹ and for educating children with disabilities,¹³⁰ and the similarity between educating the developing brain and rehabilitating the injured brain, we believe that government officials may be receptive to political advocacy on behalf of persons with DOC, urging access to rehabilitation.

B. By Statute and Case Law

This Section describes important legislation and jurisprudence that address disability rights, how lack of access to rehabilitation for persons with DOCs violates these laws and their purposes as currently written, what may be gained by a lawsuit under the ADA on behalf of persons with DOCs, and the role that considerations of cost plays in accommodating persons with disabilities.

1. Purpose of the Rehabilitation Act of 1973, ADA, ADAAA, and Olmstead

Some legal scholars argue that certain pieces of legislation actually interpret the Constitution and define positive rights that the Constitution failed to unenumerated.¹³¹ In particular, legislation can help define broad constitutional purposes such as liberty, equality, and a strong national government.¹³² It is through legislation that positive—rather than solely negative—rights may more legitimately be created.¹³³

This perspective on how legislation can and should aid in interpreting the Constitution may not be widely shared, especially by the Supreme Court Justices themselves.¹³⁴ However, even conservative Supreme Court Justices note the importance of major rights being created or announced through legislation rather than through the courts under a substantive due process, liberty-based analysis.

¹²⁹ See Ryan, *supra* note 116, at 49-50.

¹³⁰ See 20 U.S.C. § 1400(d)(1)(A).

¹³¹ See, e.g., Rubin, *supra* note 107, at 1694.

¹³² *Id.* at 1669.

¹³³ *Id.* at 1668 (arguing that the next step in realizing the Constitution's main purposes is to recognize positive rights)

¹³⁴ *Id.* at 1693-94.

This perspective was reaffirmed in the strongly worded dissents in the recent *Obergefell* decision,¹³⁵ lamenting that the Court decided that gay marriage was a right instead of allowing the country to come to this outcome through a democratic process.¹³⁶

Whether one views the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 1990, or the Americans with Disabilities Act Amendments Act (ADAAA) of 2008 as interpreting constitutional values or being policy decisions enacted by democratically elected politicians, these pieces

135 See, e.g., *Obergefell v. Hodges*, 135 S. Ct. 2584, 2620 (2015) (Roberts, J., dissenting) (“Our cases have consistently refused to allow litigants to convert the shield provided by constitutional liberties into a sword to demand positive entitlements from the State.”); *id.* at 2631 (Thomas, J., dissenting) (“Since well before 1787, liberty has been understood as freedom from government action, not entitlement to government benefits.”).

136 See e.g., *id.* at 2642 (Alito, J., dissenting) (“The Members of this Court have the authority and the responsibility to interpret and apply the Constitution. Thus, if the Constitution contained a provision guaranteeing the right to marry a person of the same sex, it would be our duty to enforce that right. But the Constitution simply does not speak to the issue of same-sex marriage. In our system of government, ultimate sovereignty rests with the people, and the people have the right to control their own destiny. Any change on a question so fundamental should be made by the people through their elected officials.” (quoting *United States v. Windsor*, 133 S. Ct. 2675, 2715-16 (2013))).

Law professors have made similar observations as the dissenting justices in *Obergefell*. For example, Professor Rubin notes that some believe that courts should not be asserting positive rights, which is a policy decision best left to legislatures, which are accountable to the people in ways that unelected federal judges are not. See Rubin, *supra* note 107, at 1706-07, 1710. Even when judges do assert positive rights, they still often nod to the importance of the legislature in asserting them. See, e.g., *Obergefell*, 135 S. Ct. at 2591 (“While the Constitution contemplates that democracy is the appropriate process for change, individuals who are harmed need not await legislative action before asserting a fundamental right.”); see also *id.* at 2605 (majority opinion) (“Of course, the Constitution contemplates that democracy is the appropriate process for change, so long as that process does not abridge fundamental rights.”).

Liberal Justices would also prefer that social change occur through other branches of government. For example, Professor Bagenstos notes that Justice Ginsburg thinks that social change through the courts should be incremental and accomplished in tandem with other branches of the government. See Samuel R. Bagenstos, *Justice Ginsburg and the Judicial Role in Expanding “We the People”*: *The Disability Rights Cases*, 104 COLUM. L. REV. 49, 50, 56-59 (2004) (“[C]ourts could not make broad-scale social change alone but must do so in dialogue with more representative, participatory institutions of government.”). The reason for this is described well by Chief Justice Roberts in his *Obergefell* dissent:

When decisions are reached through democratic means, some people will inevitably be disappointed with the results. But those whose views do not prevail at least know that they have had their say, and accordingly are—in the tradition of our political culture—reconciled to the result of a fair and honest debate. In addition, they can gear up to raise the issue later, hoping to persuade enough on the winning side to think again . . . By deciding this question under the Constitution, the Court removes it from the realm of democratic decision.

Obergefell, 135 S. Ct. at 2625 (Roberts, C.J., dissenting).

of legislation send a clear and strong message about the U.S. government's attitude toward the disabled population. The purpose of this legislation, particularly the ADA and ADAAA, is to ensure the full participation of persons with disabilities in society; to prohibit discrimination against persons with disabilities; and to prioritize integration of persons with disabilities into their communities instead of encouraging or permitting their isolation and segregation.¹³⁷

While the Rehabilitation Act of 1973¹³⁸ was focused on aiding individuals with disabilities in gaining employment,¹³⁹ it also recognized the importance of the goals of independence and self-sufficiency even for those for whom employment would not be possible.¹⁴⁰ The ADA focused more broadly than on employment, extending section 504 of the Rehabilitation Act, which referenced nondiscrimination, giving its intent more bite.¹⁴¹ As noted by Professor Cook, the

137 As the ADA states, "[T]he Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." 42 U.S.C. § 12101(a)(7) (2012).

138 Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (codified as amended in scattered sections of 29 U.S.C. §§ 700-796).

139 *Id.* § 100(A) ("The purpose of this title is to authorize grants to assist States to meet the current and future needs of handicapped individuals, so that such individuals may prepare for and engage in gainful employment to the extent of their capabilities."); *Id.* § 400(a)(3) ("In carrying out his duties under this Act, the Secretary shall . . . promote the cause of the rehabilitation of handicapped individuals and their greater utilization in gainful and suitable employment.").

140 The Rehabilitation Act notes this in various places in the 1973 text, such as:

The purpose of this Act is to provide a statutory basis for the Rehabilitation Services Administration, and to authorize programs to . . . (3) conduct a study to develop methods of providing rehabilitation services to meet the current and future needs of handicapped individuals for whom a vocation goal is not possible or feasible so that they may improve their ability to live with greater independence and self-sufficiency."

Id. at § 2(3).

"The Secretary shall conduct a comprehensive study . . . to assist individuals with the most severe handicaps who, due to the severity of their handicaps or other factors such as their age, cannot reasonably be expected to be rehabilitated for employment but for whom a program of rehabilitation could improve their ability to live independently or function normally within their family and community.

Id. at § 130(a)(2).

141 *Id.* at § 504 ("No otherwise qualified handicapped individual in the United States, as defined in section 706, shall, solely by reason of his handicap, be excluded from the participation in or be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.").

Writing about section 504 of the Rehabilitation Act, Professor Cook asserted:

ADA's findings section "make[s] it plain as it could be that the primary evil addressed in the ADA was the segregation that continues to impose an isolated, denigrated existence upon persons with disabilities."¹⁴² The ADA was intended as

"As a remedy for segregated public services, the Rehabilitation Act and its contemporaneously enacted regulation have been practically a dead letter Adults with disabilities seeking access to integrated residential and community services have fared little better. Appellate courts, ignoring substantial section 504 arguments, have permitted government agencies to confine and isolate persons with disabilities in remote institutions, nursing homes, and other segregated facilities When it comes to the segregation of persons with disabilities, federal compliance officers have largely turned their heads."

Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 64 TEMP. L. REV. 393, 394-96 (1991). Thus, "[i]n the ADA, Congress determined, as apparently did the Executive, that section 504 simply was not working as a means of eradicating discrimination and segregation in this country." *Id.* at 416. Cook asserted that the blind, deaf, and persons with mobility disabilities were more successful in 504 claims, but not those segregated in "isolated settings." *Id.* at 396.

In *Olmstead v. L.C. ex rel. Zimring*, the Supreme Court also recognized the evolution of protection for persons with disabilities over time. 527 U.S. 581, 599 (1999) ("The ADA stepped up earlier measures to secure opportunities for people with developmental disabilities to enjoy the benefits of community living."). Unlike earlier legislation like the Rehabilitation Act, the ADA asserts that segregation of persons with disabilities is discrimination. *Id.* at 600.

142 Cook, *supra* note 141, at 398. Polling done just a few years prior to the passage of the ADA showed that the disabled were much less likely than the non-disabled to attend events in their communities. See Robert L. Burgdorf, Jr., "Equal Members of the Community": *The Public Accommodations Provision of the Americans with Disabilities Act*, 64 TEMP. L. REV. 551, 554-55 (1991). The reasons they cited were not feeling welcome and also barriers to participation (such as architectural barriers). *Id.* This means that they are highly isolated relative to other persons. *Id.*

Cook also draws a connection between state-sponsored segregation of the disabled with state-sponsored segregation based on race. Cook, *supra* note 141, at 404-07.

Congress made it plain in the ADA's legislative history that it believed the evils of segregation by race to be the same as the evils of segregation by disability. Congress regarded *Brown* as an equally important basis for eradicating disability segregation as it had been in striking down classifications based on race.

Id. at 410. He cites the statements of several members of Congress that linked segregation based on race to that based on ability status. *Id.* at 410 n.120. In both cases, segregation causes harm, and is a violation of civil rights. Importantly, however, the courts have not recognized disability to be a suspect class, receiving higher scrutiny in Equal Protection cases, and so the ADA becomes very important in protecting the civil rights of persons with disabilities. For a discussion of courts' "deferential standard of review to state-imposed classifications based upon disability," and how Congress responded by raising the standard of review by enacting the ADA, see *id.* at 433-34, 438. In fact, Congress modeled language in the ADA after language in the 1964 Civil Rights Act, which in Cook's view shows that Congress intended discrimination on the basis of disability to be taken as seriously as discrimination on the basis of race. *Id.* at 438-39.

Other scholars have also focused on the connection between the civil rights movement and the

“a comprehensive piece of civil rights legislation [that] promises a new future: a future of inclusion and integration, and the end of exclusion and segregation.”¹⁴³

disability rights movement. *See, e.g.*, FINS, RIGHTS COME TO MIND, *supra* note 9, at 286-311; Bagenstos, *supra* note 136, at 51, 55.

Some have critiqued how the ADA was modeled after the Civil Rights Act of 1964, however. Bonnie Poitras Tucker, *The ADA's Revolving Door: Inherent Flaws in the Civil Rights Paradigm*, 62 OHIO ST. L.J. 335, 342-43 (2001) (arguing that the ADA should instead have been based on “human” rights principles). Tucker writes, “As a civil rights law the ADA purports to require equal treatment for people with disabilities. In recognition of the fact that equal treatment does not lead to inclusion in the mainstream for many people with disabilities, however, the ADA requires different treatment for people with disabilities.” *Id.* at 345. Tucker argues that unlike in the case of race, disability often requires affirmative action on behalf of or differential treatment toward the disabled (rather than “equal” treatment) in order to result in equal outcomes; that is, “reasonable accommodations” are “affirmative action.” *Id.* at 354. Tucker notes that “[s]ince equal treatment of people with disabilities often leads to unequal results, different treatment is required to ensure equivalent results.” *Id.*

Tucker also discusses the differences between discrimination on the basis of race (often intentional and active) and that based on disability (often passive). *Id.* at 363-64. She writes that “[t]he more frequent scenario concerning different treatment of people with disabilities involves not the deliberate, affirmative exclusion from programs or activities, but the passive failure to provide affirmative assistance to make inclusion possible.” *Id.* at 364. This again makes the modeling of the ADA after the Civil Rights Act of 1964 problematic, since while action can be race-neutral, it cannot really be disability-neutral given that disability is a relevant difference in how one is treated. *Id.* at 365-66.

143 Cook, *supra* note 141, at 425 (quoting H.R. REP. NO. 101-485, pt. 3 at 26 (1990)). As an example of the excitement with which disability advocates viewed the ADA, see the following assessment just after its passage:

The Americans with Disabilities Act (“ADA”) is a landmark piece of legislation guaranteeing the civil rights of forty-three million Americans with disabilities. The ADA is the most significant civil rights legislation since the Civil Rights Act of 1964. Its enactment will profoundly change the legal rights of individuals with disabilities. The ADA points toward a future in which its promise of civil rights will join existing programs of financial support to create meaningful equality of opportunity for disabled individuals.

Nancy Lee Jones, *Overview and Essential Requirements of the Americans with Disabilities Act*, 64 TEMP. L. REV. 471, 471 (1991). *But see* Mary Johnson, *Before Its Time: Public Perception of Disability Rights, the Americans with Disabilities Act, and the Future of Access and Accommodation*, 23 WASH. U. J.L. & POL’Y 121, 136-37 (2007) (discussing how the actual ADA is not exactly civil rights legislation). Johnson writes:

After the revisions, the bill read less like a true civil rights law than a strange hybrid based on the understanding our national legislators and their staffs had about disability law. It was based on the understanding that disability law was a kind of benefits-based legislation that gave something to a group of people—like Social Security, disability benefits, or rehabilitation services, services that you only got if you qualified as disabled. . . . Disability was still viewed as a medical problem making one incapable of working (and, with a doctor’s okay,

Such integration would often require modifications and auxiliary aids and services, unless providing such accommodations would be an undue hardship or fundamentally alter a program.¹⁴⁴

Although Congress originally enacted the ADA in 1990, Congress amended it in 2008 in legislation entitled Americans with Disabilities Amendments Act (ADAAA), in response to courts limiting protection for the disabled in a way Congress had not intended.¹⁴⁵ Congress stated:

[I]n enacting the Americans with Disabilities Act of 1990 (ADA), Congress intended that the Act “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” and provide broad coverage [T]he holdings of the Supreme Court . . . have narrowed the broad scope of protection intended to be afforded by the ADA, thus eliminating protection for many individuals whom Congress intended to protect.¹⁴⁶

Congress responded by rejecting the Supreme Court’s narrow interpretation of disability¹⁴⁷ and clearly affirming commitment to the original purposes of the

entitled to benefits) when the ADA was enacted. Disability rights activists had conceived it as a civil rights law, but almost nobody else understood what ‘civil rights’ could possibly mean when it came to disabled people.

Id. at 136-38. This lack of understanding extended to judges who viewed the ADA as “a form of public benefit program for people with disabilities rather than a mandate for equality.” *Id.* at 139 (quoting Matthew Diller, *Judicial Backlash, the ADA and the Civil Rights Model*, 21 BERKELEY J. EMP. & LAB. L. 19, 23 (2000)). Disability advocates wanted the ADA to be treated as an antidiscrimination statute rather than as an entitlement program. *Id.* at 141.

144 Cook, *supra* note 141, at 428, 430. For a critique of how the ADA provides exceptions for cost or business considerations unlike other civil rights legislation, see Johnson, *supra* note 143, at 123, 127 (“The ADA is a civil rights act with an economic loophole built in: it says if assuring rights of access cost too much they do not have to be granted.”).

145 Some scholars have argued that courts limited the promise of the ADA because they were uncomfortable with the affirmative action required by this piece of legislation. See, e.g., Tucker, *supra* note 142.

146 Americans with Disabilities Amendments Act of 2008, Pub. L. No. 110-325, § 2(a)(1), (4), 122 Stat. 3553, 3553 (quoting 42 U.S.C. § 12101(b)(1) (2012)).

147 *Id.* at § 12101(b). For a discussion of how the ADAAA modified the ADA, see Alex B. Long, *Introducing the New and Improved Americans with Disabilities Act: Assessing the ADA Amendments Act of 2008*, 103 NW. L. REV. COLLOQUY 217. Professor Long describes how the ADA was a disappointment in the employment context because the Supreme Court narrowly construed “disability.” *Id.* at 217-18. The ADAAA was amended to reject this narrow definition. *Id.* at 219-21.

Johnson argues that the reason the courts did not find for disabled plaintiffs under the original

ADA.

The history of disability rights legislation is one of increasing protection for those with disability. The ADA extended the Rehabilitation Act's nondiscrimination protections to cover entities that do not receive federal funds.¹⁴⁸ The ADAAA expanded upon the ADA to broaden the definition of disability. Despite these expansions, there are still gaps in the legislation. For example, there are still significant questions about what constitutes reasonable accommodations or modifications. These terms are not defined in either the ADA or the ADAAA, and when the courts address the issue, the cases tend to be too fact-specific to act as precedent.¹⁴⁹ To date, neither legislation nor case law addresses what reasonable accommodations or modifications are for persons with DOCs.

Olmstead is the leading Supreme Court case interpreting the Title II of the ADA as promoting integration of the disabled into mainstream society when possible.¹⁵⁰ The ADA explicitly asserts that segregation of the disabled is a form

version of the ADA was because they did not fully understand the principles of the ADA. She asserts that the reason judges did not understand the principles is that the legislation was passed based on the lobbying of disability rights activists who did not also lobby the public or the media, explaining the reasons disability rights legislation was needed. Johnson, *supra* note 143, at 121-22. She contrasts the ADA with other civil rights legislation, which was publicly discussed; unlike the Civil Rights Act of 1964, most Americans did not know about the ADA. *Id.* at 123. Another reason why Congress's intent was not implemented was because of the backlash to the ADA that played out in the press, stating that unlike other pieces of civil rights legislation that just prohibited action, the ADA required affirmative obligations that were costly ("special benefits"). *Id.* at 130-31; *see also* Tucker, *supra* note 142, at 337-40 (arguing that the ADA was passed before Americans were ready to accept its principles and there has thus been backlash). The way to limit the ADA was to limit to whom the ADA applied, and thus the definition of disability was limited. Johnson, *supra* note 143, at 132. *But see* Stephen L. Mikochik, *The Constitution and the Americans with Disabilities Act: Some First Impressions*, 64 TEMP. L. REV. 619, 624-25 (1991) (asserting that the ADA was discussed and debated over years at both the federal and state government level and thus "did not steal upon unsuspecting states"); *see also* Jones, *supra* note 143, 472-75 (describing the lengthy process of passage of the ADA). While Johnson appears to fault disability rights activists for not making their case for the passage of the ADA to the press, one could just as easily fault journalists for failing to cover the proposed legislation.

148 Johnson, *supra* note 143, at 126; Jones, *supra* note 143, at 475-76 ("A key rationale used to support the ADA was that it essentially extended into the private sector an existing federal statute.").

149 Long, *supra* note 147, at 228 ("[T]he few times the Supreme Court has addressed the concept of reasonable accommodation or reasonable modification, the cases have been so fact specific as to provide little guidance for future cases."); *see also* Jones, *supra* note 143, at 479.

150 Writing for the Court, Justice Ginsburg stated:

[W]e conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate,

of discrimination, which the legislation seeks to eliminate.¹⁵¹ Writing for the Court, Justice Ginsburg noted the connection between segregation of persons with disabilities in institutions and discrimination:

Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments. First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.¹⁵²

Although *Olmstead* specifically considered whether the institutionalization of those with intellectual disabilities was a violation of Title II of the ADA, its reasoning about isolation and segregation and the connection to discrimination

the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 607 (1999).

For a discussion of the limitations of *Olmstead*, see David Fergeler, *The Constitutional Right to Community Services*, 26 GA. ST. U. L. REV. 763 (2009-10). Fergeler focuses on the lack of definition for key terms in the Court's qualified holding. He argues that by not providing precise definitions, states have latitude to keep persons with intellectual disabilities in institutions for no rational reason. *Id.*

¹⁵¹ See Cook *supra* note, 141, at 399-414 (describing a history of state-sponsored segregation of persons with disabilities). But see *Olmstead*, 527 U.S. at 623 (Thomas, J., dissenting) ("At bottom, the type of claim approved of by the majority does not concern a prohibition against certain conduct (the traditional understanding of discrimination), but rather imposition of a standard of care."); see also Tucker, *supra* note 142 (discussing how the Justices are uncomfortable with the reality that eliminating discrimination requires affirmative action in the case of disability).

¹⁵² *Olmstead*, 527 U.S. at 600-01 (internal citations omitted).

similarly applies to those in a MCS and to Title III of the ADA.¹⁵³ The assumptions of “incapable” and “unworthy” point to an assessment of the potentiality of persons with a DOC, particularly those in the MCS.¹⁵⁴ Their potentiality is unknown, however, if there are no rehabilitative interventions. These brain-injured but conscious persons are assumed to be unable to participate in society, and so are segregated in custodial care, with diminished quality of life. They are also not integrated into the community because they are not given access to functional communication (referring generally to neuroprosthetics and rehabilitative technologies).¹⁵⁵ Failure to provide this is unlawful discrimination.¹⁵⁶

2. How Lack of Access to Rehabilitation for Those in MCS Violates the ADA and Olmstead

The minimally conscious are profoundly disabled, and because of this are covered by existing disability rights legislation and court cases interpreting such legislation.¹⁵⁷ Title I of the ADA is likely not applicable to most persons in an

153 Some have argued that *Olmstead* will have an impact beyond the issue of deinstitutionalization. See, e.g., Bagenstos, *supra* note 136, at 55. This case is often referred to as the “*Brown v. Board of Education* of the disability rights movement.” *Id.* at 49. The reasons for drawing this connection between the cases are twofold, according to Bagenstos:

First, the direct holding of the case squarely attacked a practice that the disability rights movement had long mobilized against: the isolation of individuals with disabilities in congregate institutions separate from the community at large. To disability rights activists, that practice of segregation bore a striking resemblance to the Jim Crow practices attacked by the African American civil rights movement. Second—and perhaps more important—the *Olmstead* opinion marked the Court’s most expansive endorsement of the disability rights movement’s broad conception of discrimination and of its goal of integrating people with disabilities throughout the fabric of community life.

Id. at 55 (internal citations omitted).

154 *But see* Nakase-Richardson, *supra* note 55 (demonstrating that a significant proportion of this population regain functional capacity).

155 See *supra* Sections I.B, I.D, and II.A.3; see *infra* Section II.B.2. As Professor Fins has argued, linking patients to functional communication is a holy grail toward connecting people to their family and community. FINS, RIGHTS COME TO MIND, *supra* note 9, at 292-94.

156 It is important to note that while the legislation seeks to eliminate discrimination, which has many negative effects on the wellbeing of persons with disabilities, the legislation is also promoting integration, which has many positive effects on the quality of life for persons with disabilities. This is a two-pronged approach towards improving the status of the disabled. See Cook, *supra* note 141, at 455 (discussing the benefits of integration).

157 Persons with DOC meet all of the statutory requirements for disability. They have both physical and mental impairments, and these impairments substantially limit major life activities. Americans with Disabilities Act, 42 U.S.C. § 12102(1)(A) (2012) (defining disability); see Jones, *supra* note 143 (summarizing what each Title of the ADA of 1990 covers).

MCS because it relates to employment,¹⁵⁸ of which persons in a minimally conscious state are not capable. Title II may be relevant for some persons in a MCS as it concerns governmental-provided services.¹⁵⁹ Title III of the Act, however, is highly relevant as it prohibits discrimination by private entities providing public accommodations.¹⁶⁰ Hospitals and health care providers are covered in this section.¹⁶¹

Equal access to public accommodations has long been seen as a civil right.¹⁶² Title III notes that it is discrimination under the ADA if there is

[a] failure to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered or would result in an undue burden.¹⁶³

The ADA further mandates that “[g]oods, services, facilities, privileges, advantages, and accommodations shall be afforded to an individual with a disability in the most integrated setting appropriate to the needs of the individual.”¹⁶⁴ Federal regulations have expanded on these requirements.¹⁶⁵

¹⁵⁸ 42 U.S.C. § 12111.

¹⁵⁹ 42 U.S.C. § 12131.

¹⁶⁰ 42 U.S.C. § 12182(a) (“No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.”). This section covers prohibited activities such as unequal benefit or separate benefit, and also encourages integration.

Prior to the ADA, “[a] privately owned place of public accommodation, prohibited by federal law from discriminating against people on the basis of race, religion, or national origin, was not legally deterred from engaging in blatant and invidious discrimination against people with disabilities.” Burgdorf, *supra* note 142, at 556. For a detailed summary of Title III of the ADA and what it requires, see Burgdorf, *supra* note 142.

¹⁶¹ 42 U.S.C. § 12181(7)(F).

¹⁶² Burgdorf, *supra* note 142, at 552-53. Given this, such access is guaranteed in the Civil Rights Act of 1964 and also the ADA. *Id.* at 553.

¹⁶³ 42 U.S.C. § 12182(b)(2)(A)(iii).

¹⁶⁴ 42 U.S.C. § 12182(b)(1)(B).

¹⁶⁵ Americans with Disabilities Act Title III Regulations: Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, 28 C.F.R. pt. 36.303 (2016). The regulations titled “Auxiliary aids and services” states in first section:

- (a) General. A public accommodation shall take those steps that may be necessary to ensure that no individual with a disability is excluded, denied

A RIGHTS AGENDA FOR SEVERE BRAIN INJURY

While neuroprosthetics are not mentioned in the statute or regulations, they fall under the catchall provision in both the statute and the regulations about required auxiliary aids and services, entitled “[o]ther similar services and actions.”¹⁶⁶ “Scholars have recognized that “the specific requirements [of the ADA’s reasonable accommodation requirements] may vary as technological advances occur.”¹⁶⁷

The reason auxiliary aids and services must be provided is “to ensure effective communication with individuals with disabilities.”¹⁶⁸ As the regulations note:

The type of auxiliary aid or service necessary to ensure effective communication will vary in accordance with the method of communication used by the individual; the nature, length, and complexity of the communication involved; and the context in which the communication is taking place. A public accommodation should consult with individuals with disabilities whenever possible to determine what type of auxiliary aid is needed to ensure effective communication, but the ultimate decision as to what measures to take rests with the public accommodation, provided that the method chosen results in effective communication. In order to be effective, auxiliary aids and services must be provided in accessible format, in a timely manner, and in such a way as to protect the privacy and independence of the individual with a disability.¹⁶⁹

Guidance accompanying the regulations states that “[i]mplicit in this duty to provide auxiliary aids and services is the underlying obligation of a public

services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the public accommodation can demonstrate that taking those steps would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or would result in an undue burden, i.e., significant difficulty or expense.

Id. In the examples section, the regulations focus on auxiliary aids and services for the deaf or hard of hearing, the blind or low vision, and have a catchall provision “Other similar services and actions.” *Id.*

¹⁶⁶ Compare 42 U.S.C. § 12103(1)(D) (adopting this catchall category), with 28 C.F.R. § 36.303(b)(4) (same).

¹⁶⁷ Jones, *supra* note 143, at 495.

¹⁶⁸ 28 C.F.R. § 36.303(c).

¹⁶⁹ *Id.* § 36.303(c)(1)(ii).

accommodation to communicate effectively with customers, clients, patients, companions, or participants who have disabilities affecting hearing, vision, or speech.”¹⁷⁰ The statute, regulations, and interpretive guidance imply that healthcare providers have a legal obligation to provide aids and services (such as the rehabilitative technologies previously discussed) in order to assist persons with DOCs in communicating with their treatment providers and caregivers. Indeed, lack of such aids and services is likely to lead to substandard care, although this has not been litigated in the courts. If patients with a DOC are actually minimally conscious and can experience pain, but are not given access to the tools to communicate with their healthcare provider, this is, in our view, a violation of the ADA and, more importantly, simply inhumane.¹⁷¹

Notably, “auxiliary aids” do not have to be the most technologically advanced or expensive—they just have to result in effective communication with the person with a disability.¹⁷² In the context of patients in a MCS, this may mean

170 Department of Justice, Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, 28 C.F.R. pt. 36, app. A, at 133 (2010) (providing guidance for ADA Title III Regulations).

171 Palliative care and tending to pain relief is important for seriously ill patients. See JOSEPH J. FINS, *A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE’S END* (2006) (describing barriers to palliative care, and the need to plan for palliative care); Robert A. Burt, *The Supreme Court Speaks—Not Assisted Suicide but a Constitutional Right to Palliative Care*, 337 NEW ENG. J. MED. 1234 (1997) (arguing that *Washington v. Glucksburg* requires states to not obstruct the provision of palliative care).

172 The ADA Title III Regulations state under “alternatives” that

[i]f provision of a particular auxiliary aid or service by a public accommodation would result in a fundamental alteration in the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or in an undue burden, i.e., significant difficulty or expense, the public accommodation shall provide an alternative auxiliary aid or service, if one exists, that would not result in an alteration or such burden but would nevertheless ensure that, to the maximum extent possible, individuals with disabilities receive the goods, services, facilities, privileges, advantages, or accommodations offered by the public accommodation.

28 C.F.R. § 36.304(g). The accompanying guidance states:

As the Department noted in the preamble to the NPRM, the list of auxiliary aids in section 36.303(b) is merely illustrative. The Department does not intend that every public accommodation covered by title III must have access to every device or all new technology at all times, as long as the communication provided is effective.

28 C.F.R. pt. 36, app. A, at 115. Further guidance states:

The Department understands that there are many new devices and advances in technology that should be included in the definition of available auxiliary aids .

that entities providing treatment or care may choose to provide access to a communication board (or similar low-cost communication device)¹⁷³ or to drugs in a first attempt at low-cost but effective communication. If these interventions do not result in effective communication, however, then hospitals and custodial care facilities may be required under ADA Title III to provide access to neuroimaging to aid in effective communication with the patient in the MCS.¹⁷⁴

We assert that when persons in a MCS are segregated into “custodial care” and not provided access to auxiliary aids or services that may assist them in communicating with their treatment providers, that this violates the ADA and *Olmstead*.¹⁷⁵ This lack of integration is discrimination under the ADA, and violates the very purpose of the statute.¹⁷⁶ Moreover, patients with DOCs are not just receiving segregated services, but often are not receiving services at all, and instead are just institutionalized.

While Justice Kennedy in his *Olmstead* concurrence notes that “segregation and institutionalization are [not] always discriminatory,”¹⁷⁷ we assert that in the case of minimally conscious persons receiving custodial care rather than inpatient rehabilitation, this is a form of discrimination under the ADA and is unlawful under the logic of the majority’s *Olmstead* opinion.¹⁷⁸ The lack of access to

. . . While much of this technology is not expensive and should be available to most title III entities, there may be legitimate reasons why in a particular situation some of these new and developing auxiliary aids may not be available, may be prohibitively costly (thus supporting an undue burden defense), or may otherwise not be suitable given other circumstances The Department recognizes that the available new technology may provide more effective communication than existing technology and that providing effective communication often will include use of new technology However, the Department has not mandated that title III entities make all technology or services available upon demand in all situations.

Id. at 122. This is in context of technology for deaf or hard of hearing individuals, but is just as applicable to those with a DOC. See also Dalia B. Taylor, *Communicating with Vegetative State Patients: The Role of Neuroimaging in American Disability Law*, 66 STAN. L. REV. 1451, 1468-69 (2014) (describing this guidance as applied to this population).

173 See, e.g., SPEAK YOUR MIND FOUNDATION, *supra* note 58 (describing low-cost communication devices for persons with severe brain injury).

174 See Taylor, *supra* note 172, at 1471-83 (analyzing whether a court would find that access to brain scanning for persons with DOC would be considered an auxiliary aid under the ADA, and arguing that this claim would likely succeed).

175 FINS, RIGHTS COME TO MIND, *supra* note 9, at 296-305.

176 *Id.*

177 *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 614 (1999) (Kennedy, J., concurring); see also *id.* at 607 (Stevens, J., concurring) (emphasizing that it is “unjustified institutional isolation” that is discrimination under the ADA).

178 *Id.* at 600-01, 607 (majority opinion).

rehabilitative technologies that fall under the category “auxiliary aids and services” also violates Title III of the ADA.

3. Legal Remedies Available to Persons with DOCs Under the ADA

Because the existence of the MCS has only been recently recognized, and because persons in a MCS are often isolated in custodial care, there has not been a disability rights movement around consciousness.¹⁷⁹ In fact, application of the ADA to this group has only recently been discussed in the legal literature.¹⁸⁰ Professor Fins began the call for a legal remedy for these individuals in 2010.

Instead, it is respect and regard for civil rights and the more fundamental issue that conscious individuals, who might be embraced more fully by our shared human community, are routinely ignored, sequestered, and segregated. This is an utter breach of their inalienable rights, rights that in this case may be dependent upon the provision of interventions, which remain experimental but will likely be expensive and scarce. Because of this it is important to view this technology as enabling a fundamental right to be enjoyed by all citizens, a class utterly dependent upon the goodwill of others, and their recognition of their reciprocal ethical obligation to provide access to technology that will restore their voice and given them more equal opportunities. If these responsibilities are not recognized by our common morality, they should be enforced by law.¹⁸¹

However, the ADA can provide remedies for persons in a MCS who are isolated and segregated, without access to rehabilitation, which may aid in their communication and subsequent community integration. Lawsuits brought under

179 Fins, *RIGHTS COME TO MIND*, *supra* note 9, at 302, 304, 310 (arguing that persons with DOCs are not seen as disabled, and instead are seen as sick or nearly dead, and so do not have protections of others persons with disabilities). Furthermore, the families of those with DOCs are “too burdened by caregiving to engage in the social action necessary to initiate and sustain a social movement.” They are instead spending their time fighting for appropriate, quality care for their disabled family member. *Id.* at 310; *see also* Fins, *Minds Apart*, *supra* note 30, at 380 (describing how in comparison to advocates of those with intellectual disabilities, “no comparable political prowess exists for advocates of those with disorders of consciousness”).

180 *See e.g.*, FINS, *RIGHTS COME TO MIND*, *supra* note 9, at 302 (“Until now, to my knowledge, no one has made an ADA claim for this population.”); Fins, *Minds Apart*, *supra* note 30, at 377. Professor Fins’ argument predated by a few years an argument that would be made by a Stanford Law School student who argued for a right to neuroimaging devices under the ADA for those with DOC. *See* Taylor, *supra* note 172.

181 Fins, *Minds Apart*, *supra* note 30, at 377.

the ADA may lead to injunctive relief.¹⁸²

[I]njunctive relief shall include an order to alter facilities to make such facilities readily accessible to and usable by individuals with disabilities to the extent required by this subchapter. Where appropriate, injunctive relief shall also include requiring the provision of an auxiliary aid or service, modification of a policy, or provision of alternative methods, to the extent required by this subchapter.¹⁸³

In this case, advocates for the minimally conscious and those with other DOC that may progress to a MCS¹⁸⁴ may sue for access to rehabilitation while in custodial care, which can be construed as an “auxiliary aid”¹⁸⁵ so that they can be integrated into the community.¹⁸⁶

As the Guidance for the 2010 regulations of the ADA note, “When a public accommodation ignores the communication needs of the individual requiring an auxiliary aid or service, it does so at its own peril, for if the communication provided is not effective, the public accommodation will have violated title III of the ADA.”¹⁸⁷ Litigation on behalf of a patient in a MCS may have lasting social change.¹⁸⁸ Successful litigation would provide notice to hospitals and physicians

182 For a critique of this sole remedy, see Johnson, *supra* note 143, at 128. She describes how in political compromises to get the ADA of 1990 passed, the section on damages was dropped. *Id.*

183 Americans with Disabilities Act, 42 U.S.C. § 12188(a)(2) (2012).

184 But, currently “[n]o advocacy group specifically addresses the needs of patients with disorders of consciousness.” Fins, *Minds Apart*, *supra* note 30, at 380.

185 See *supra* notes 163-175 and accompanying text.

186 Taylor, *supra* note 172, argues that the Rehabilitation Act and the ADA may require hospitals to provide neuroimaging to persons with DOC, but does not broaden her argument to rehabilitation generally, which would also include access to drugs and other neuroprosthetics. She predicts that “[c]ourts may have to determine whether these federal auxiliary aid requirements obligate hospitals and other health care facilities to provide neuroimaging technology as a mode of communication for otherwise uncommunicative or vegetative state patients.” *Id.* at 1454. She suggests that “[r]epresentatives of vegetative state or minimally conscious state patients could one day take advantage of these Acts to sue for injunctions mandating that health care facilities provide brain-scanning technology as a means of communication.” *Id.* at 1465. For a discussion of standing issues related to plaintiffs with DOC, see *id.* at 1466-67.

187 Department of Justice Guidance, 28 C.F.R. pt. 36, app. A, at 118. Additionally, the guidance recommends ongoing communication assessments of a person with a disability due to changing needs. *Id.* (“This dialogue should include a communication assessment of the individual with a disability initially, regularly, and as needed, because the auxiliary aids and services necessary to provide effective communication to the individual may fluctuate.”).

188 For a brief review of factors that indicate whether “litigation will affect social change,” see Ryan, *supra* note 116 at 90. Writing in the context of whether litigation would be successful in creating a right to preschool, Ryan noted:

that the ADA applies to those with DOCs, which may lead to prioritizing an accurate diagnosis for those with a DOC and to providing access to rehabilitative technologies to aid in communication, in an attempt to avoid costly lawsuits.

Widespread medical change with respect to DOCs is to be preferred to litigation, which is a lengthy process, during which time the person or class of persons with DOCs may suffer irreparable harm including death, illness, or an impaired quality of life because of inadequate access to medical and rehabilitative interventions. Furthermore, there is a risk that litigation may not be successful, if defendants prevail on available defenses under the ADA, by, for example, claiming that rehabilitative technologies pose an “undue burden” on the provider. Changes in medical practice could be accelerated, however, if there first were successful litigation under the ADA.

As one of us previously argued, “Access to neuroprosthetic technologies, drugs, and devices that might restore functional communication cannot be viewed as a mere entitlement to be funded or cut, a benefit to be shaved in a tight budget year, or a service at the margins.”¹⁸⁹ This is not only so because to deny such access is profoundly unethical, but also because it violates the mandates of the ADA and *Olmstead*.

Importantly, however, we are not arguing that all persons with DOCs should be given rehabilitation or moved out of custodial care. As the *Olmstead* majority noted, “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or

[S]cholars have identified a set of factors that make it more or less likely that litigation will affect social change. These factors include: the intensity of opposition; whether legislators and administrators view court orders as helpful political cover for leveraging more resources for programs they already favor; whether market mechanisms will help implement the newly created right; the ease with which rulings can be evaded; and the determination, resources, and strategies of those seeking to enforce the right.

Id. In the case of a right to rehabilitative technologies for patients with a DOC, we do not foresee opposition except perhaps from those concerned with costs or for those who think the right to die may be threatened. Legislators do support integration of persons with disabilities, and a court ruling may provide political cover if such integration increases costs, which may not be as popular with constituents. There is a market for technological interventions that may aid in integrating persons with DOCs in society. If there is sustained attention to the issue of integration, court rulings mandating access to rehabilitation cannot be evaded. The final factor may be the one that is most problematic for advocates of patients with DOC. They may not have the time to sustain their legal challenge and to pursue lasting social change outside of their individual remedy. On the whole, however, we think litigation could affect social change for this population.

189 Fins, RIGHTS COME TO MIND, *supra* note 9, at 294.

benefit from community settings.”¹⁹⁰ For those with recent injuries and who are still in a coma, rehabilitation may not be appropriate. For those in a VS, rehabilitation may not be appropriate (it may, however, if it could assist them in recovering consciousness to some degree). Rehabilitation would clearly be ineffective in a patient properly diagnosed as being in a permanent vegetative state. However, given the rates of misdiagnosis, it is ethically and clinically imperative that, before patients are categorized as permanently unconscious, that this classification is vetted and appropriate. Furthermore, the diagnosis may only be ascertained, and the degree of the patient’s true function only understood, through interventions such a drug trial with agents like amantadine or zolpidem or speech or physical therapy, which might elicit findings that could critically upgrade their diagnostic state from the VS to MCS. Thus, it necessary to conduct a proper assessment to determine whether someone is actually in a permanent vegetative state¹⁹¹ prior to discharging a patient to chronic care rather than rehabilitation.¹⁹²

4. Counterarguments and Rebuttals

The most significant objection to recognizing a right to rehabilitation for the brain-injured person with a DOC under the ADA is that the provision of such rehabilitation may be cost-prohibitive or difficult to implement. In other words, providing access to rehabilitative technologies for persons with DOCs may constitute an “undue burden,” which is an available defense under the ADA for not providing a particular accommodation.¹⁹³ We will also address cost in a later

190 *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 583; *see also id.* at 610 (Kennedy, J., concurring) (“It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that the States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision [I]f the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.”); *see also* Bagenstos, *supra* note 136, at 58 (“One might regard these qualifications as improperly diluting the right to integration that was at stake in *Olmstead*. But it is possible to see them, instead, as a recognition of the limited capacity of courts to shoulder the burden of significant social change on their own.”). *But see* Cook, *supra* note 141, at 442-45 (arguing that all persons with disabilities should receive services in the community). In the case of DOCs, deinstitutionalization is not solely about social change, but is also about the ability of persons with DOC to be in the community.

191 Some patients may be thought to be in a permanent vegetative state, but are actually in a nonbehavioral MCS. FINS, RIGHTS COME TO MIND, *supra* note 9, at 131-33 (summarizing research on nonbehavioral MCS).

192 *Id.* at 93-95 (describing the role of McKesson Health Solutions, LLC’s InterQual Criteria in denying rehabilitation to patients in a DOC who could potentially benefit from such care).

193 28 C.F.R. § 36.303(a) (2016) (defining “undue burden” as “significant difficulty or expense”).

Section,¹⁹⁴ but will assert here that many of the rehabilitative technologies discussed in this paper are unlikely to be an undue burden on the entity providing public accommodations.¹⁹⁵

Given this particular population of persons with disabilities and where they are housed, it would likely not be an undue burden to provide them with rehabilitative technologies given that healthcare facilities should reasonably have them on hand if patients are in a venue appropriately suited to their rehabilitative needs.¹⁹⁶ It remains a question whether the custodial care facilities in which many persons with DOCs are living have the actual resources to provide appropriate rehabilitative technologies. But even in facilities that do not have access to the emerging technologies referenced here, they should provide cheaper, readily available alternatives such as access to communication boards, drugs, and the services of neurorehabilitative specialists.¹⁹⁷

Whether one agrees that the ADA is wise social policy, it is law and must be followed. The enacting legislature of the ADA intended for persons with disabilities to be fully integrated in society and a subsequent legislature amended the legislation to be stronger than courts had originally interpreted the ADA. As Justice Marshall noted in his partially concurring opinion in *City of Cleburne v. Cleburne Living Center*, a case about a zoning ordinance that prevented a group home for the intellectually disabled from being located at a certain site:

Courts, however, do not sit or act in a social vacuum. Moral philosophers may debate whether certain inequalities are absolute wrongs, but history makes clear that constitutional principles of equality, like constitutional principles of liberty, property and due process, evolve over time; what once was a ‘natural’ and ‘self-evident’ ordering later comes to be seen as artificial and invidious constraint on human potential and freedom. Shifting cultural, political, and social patterns at times come to make past practices appear inconsistent with fundamental principles upon which American society rests, an inconsistency legally cognizable under the Equal Protection Clause. It is natural that evolving standards of equality come to be embodied in legislation. When that occurs, courts should look

¹⁹⁴ See discussion *infra* Section III.3.

¹⁹⁵ Of course, this would become a moot point if such rehabilitative interventions were covered by insurers. See discussion *infra* Section III.1.

¹⁹⁶ See Taylor, *supra* note 172 (arguing that the “undue burden” defense would not apply in most instances of requesting neuroimaging); see also Burgdorf, *supra* note 142, at 578 (discussing “undue burden” as it applies to small businesses); Fins et al., *supra* note 22.

¹⁹⁷ See Burgdorf, *supra* note 142, at 580. The precise scope and nature of required services is within the domain of implementation science.

to the fact of such change as a source of guidance on evolving principles of equality.¹⁹⁸

We assert that the ADAAA of 2008 embodies evolving standards of equality in regard to persons with disabilities. If faced with a lawsuit that requests access to neuroprosthetics or other assistive devices for those with DOCs in order to aid them in communicating with their healthcare providers and caregivers and also to promote community integration, we argue that courts should find for the plaintiffs.

III. REFORMS TO REALIZE THE RIGHT TO REHABILITATION

Once a right to rehabilitation of the brain-injured minimally conscious patient is recognized—either as analogous to the expectation of free public education for children with developing brains or as a statutory right under the ADA—there must be legal and policy reforms. We have already noted the need for access to auxiliary aids and devices to assist in communication between the minimally conscious and their healthcare providers and caregivers, as mandated by the ADA. In this Part, we address some other necessary changes and objections to these changes. We do not address all possible reforms to realize the right to rehabilitation, including how our argument intersects with the Affordable Care Act, as that is beyond the scope of this Article.¹⁹⁹

A. Proposed Changes to Medicare Policies

Disability scholars have noted that rights alone are insufficient to achieve equality in the realm of disability. For example, Professor Bagenstos noted that Title I of the ADA, which prevents discrimination against the disabled in the context of employment, has not has the desired effect on increasing employment among persons with disabilities.²⁰⁰ This is because such a prohibition against discrimination does not address other structural barriers to employment such as

¹⁹⁸ 473 U.S. 432, 466 (1985) (Marshall, J., concurring in part and dissenting in part). Justice Kennedy echoes Justice Marshall's language on evolving standards of equality almost exactly in his recent *Obergefell* opinion. See text accompanying *supra* note 1.

¹⁹⁹.. We do not, for example, discuss many changes in medical practice that need to occur. One such change, for example, would be continued surveillance of those with DOC to determine whether they are minimally conscious. The legal implications of not surveilling such persons is that they are often institutionalized and placed under guardianship, which is a huge liberty infringement. If they are not routinely assessed for consciousness, this could constitute a violation of procedural due process. See Fergeler, *supra* note 150, at 799 (discussing this in the context of the institutionalization of the intellectually disabled.)

²⁰⁰ Bagenstos, *supra* note 136.

lack of access to healthcare, which is an entitlement.²⁰¹ His argument, in essence, is that the antidiscrimination elements of the ADA need to be combined with changes in social welfare programs.²⁰² As he notes in a recent *New York Times* commentary about the twenty-fi anniversary of the ADA, “[W]e will need not just antidiscrimination laws but social welfare programs that will overcome these barriers.”²⁰³

We also assert that the right to rehabilitation is insufficient to change the lived reality of persons with DOCs. There must also be changes to existing social welfare programs. One issue that patients with DOCs face are Medicare payment policies that may prevent them from receiving needed care. In a previous paper, we described how some groups of patients whose care was funded by Medicare alleged that they were subject to an “improvement” standard, meaning that they would not receive certain kinds of care if they were not expected to improve.²⁰⁴ If true, then this would violate Medicare’s policies; treatment and coverage decisions are supposed to be based on “medical necessity” rather than an improvement standard.²⁰⁵ These patients brought a class-action lawsuit against Medicare in *Jimmo v. Sebelius*.²⁰⁶ The parties ultimately settled when a judge refused to grant the government’s motion to dismiss, and the settlement resulted in negotiated changes to the Medicare Benefit Policy Manual between the plaintiffs’ counsel and the Centers for Medicare and Medicaid Services, explicitly noting that no patient should be subjected to such an improvement standard.²⁰⁷ The result of this settlement—the changes to the Medicare Manual—may have a ripple effect because many other payors use Medicare policies as a model.²⁰⁸

Patients with DOCs, given their severe disability, are often covered by Medicare,²⁰⁹ and thus changes due to the settlement apply to this group. If

²⁰¹ *Id.*

²⁰² *Id.*

²⁰³ Samuel Bagenstos, *Disability Laws Are Not Enough To Combat Discrimination*, N.Y. TIMES (July 26, 2015), <http://www.nytimes.com/roomfordebate/2015/07/26/the-americans-with-disabilities-act-25-years-later/disability-laws-are-not-enough-to-combat-discrimination> (writing in the context of employment, but the same is true for community integration in the case of persons with DOC).

²⁰⁴ Fins et al., *supra* note 22, at 182-183.

²⁰⁵ That is, care necessary to maintain or prevent decline should be covered, not just care that is expected to help patients improve. *See id.* at 183.

²⁰⁶ Amended Complaint, *Jimmo v. Sebelius*, No. 5:11-CV-17 (D. Vt. Oct. 25, 2011), 2011 WL 5104355.

²⁰⁷ *Jimmo v. Sebelius Settlement Agreement Fact Sheet*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/medicare/medicare-fee-for-service-payment/SNFPSPS/downloads/jimmo-factsheet.pdf> (last visited on Oct. 1, 2016).

²⁰⁸ Fins et al., *supra* note 22, at 182.

²⁰⁹ Persons with disabilities are often insured through Medicare, Medicaid, or both. *See* Sandra M. Foote & Christopher Hogan, *Disability Profile and Health Care Costs of Medicare*

A RIGHTS AGENDA FOR SEVERE BRAIN INJURY

patients with DOCs were subjected to the alleged improvement standard, there is little doubt they would not meet such a standard. As a result, most would be denied care that may enable them to recover or at least “maintain” their present mental state and prevent further decline. So the *Jimmo* settlement could be considered a “win” for patients with DOCs. Unfortunately, however, “medical necessity” is still the Medicare standard, and it is difficult for patients with DOCs to demonstrate that inpatient rehabilitation is medically necessary. Moreover, simply being “maintained” in their current condition is not sufficient to trigger coverage of inpatient rehabilitation.²¹⁰

In our previous work, we have recommended changes to Medicare coverage policies that would be more appropriate for patients with DOC. As we noted:

We would propose expanding the definition of “reasonable and necessary” to include monitoring, rehabilitation, and therapy for MCS and view this heightened level of care as a new standard of care. This would include diagnostic, therapeutic, and rehabilitative interventions necessary to decrease diagnostic and prognostic error and maximize functional return of physical and cognitive capabilities, most notably the return of spoken language In addition to being dependent on skilled clinical care, MCS patients rely on access to a variety of drugs, devices, and diagnostic tools. This additional dependency needs to be understood within the settlement framework and the “reasonable and necessary” standard.²¹¹

B. Capabilities Approach

Expanding access to entitlements, such as in the case of our proposed Medicare changes, is not sufficient to ensure full inclusion in society for persons with DOC, but neither is the assertion of a right to rehabilitation or a right to community integration.²¹² Rather, it is a combination of entitlements grounded in rights, in particular access to resources and rehabilitative technologies that can

Beneficiaries Under Age Sixty-Five, 20 HEALTH AFF. 242, 245 ex.2 (2001).

²¹⁰ Fins et al., *supra* note 22, at 188.

²¹¹ *Id.* at 188-89.

²¹² Cf. Kaaryn Gustafson, Opinion, *More Work Needs To Be Done To Prevent Exclusion of the Disabled*, N.Y. TIMES (July 26, 2015), <http://www.nytimes.com/roomfordebate/2015/07/26/the-americans-with-disabilities-act-25-years-later/more-work-needs-to-be-done-to-prevent-exclusion-of-the-disabled> (“The A.D.A. was an important step in recognizing universal rights to dignity and inclusion among all Americans. But we have more work to do—and much of it requires a collective commitment to equality and inclusion, not just the hollow reverence we give to individual rights.”).

assist individuals in possibly achieving communication, that can help realize the right to not be segregated on the basis of disability.²¹³

For a better understanding of how to ensure the full dignity, equality, and liberty of persons with DOCs, we turn to the capabilities approach, which has been pioneered by Amartya Sen and Martha Nussbaum and recently expanded upon by Sridhar Venkatapuram in the specific context of health. This approach “asserts that societies should focus on supporting—nurturing, protecting, providing, expanding, restoring, and so forth—the capabilities of individuals to conceive, pursue, and revise their life plans” rather than focusing solely on outcomes.²¹⁴ Individual capabilities are sometimes defined as “freedoms or real opportunities to achieve beings and doings.”²¹⁵

Some scholars have identified what they consider to be core capabilities. For example, Nussbaum has a list of ten capabilities, including health; senses, imagination, and thought; and affiliation.²¹⁶ Recently, Venkatapuram has argued that the health capacity should be understood as a “meta-capacity,” which means it is necessary to exercise other capacities.²¹⁷ He defines the health capacity as “a person’s ability to achieve or exercise a cluster of basic capabilities and functionings, and each at level that constitutes a life worthy of equal human dignity in the modern world.”²¹⁸ When this and other necessary capabilities are

213 See FINS, RIGHTS COME TO MIND, *supra* note 9, at 292-94 (discussing the capabilities approach applied to persons with DOCs).

214 VENKATAPURAM, *supra* note 21, at 115 (citations omitted, summarizing work by Sen, Nussbaum, and others). Outcomes are also referred to as “functionings” or “achievements.” Nussbaum argues that the focus should be on a person’s capability rather than their achievements except when dignity is at stake. *Id.* at 135. Like Nussbaum, we would argue that if it is possible for a person with a DOC to communicate if given access to certain technologies, then we should focus on achievements or functionings rather than just capabilities because communication and community are central to human dignity. *Id.* at 135-36 (“Some functionings may be so valuable to maintaining minimal human dignity that they will not be allowed to be neglected or fail.”).

215 *Id.* at 117.

216 NUSSBAUM, *supra* note 20. With respect to persons with disabilities, Venkatapuram also describes how Nussbaum thinks that we should consider the needs of the severely disabled prior to setting up institutions rather than at the end of the process where only small accommodations can be made. VENKATAPURAM, *supra* note 21, at 150.

217 *Id.* at 143.

218 *Id.* Ensuring health capacity also requires considering and addressing the social determinants of health. As Venkatapuram argues:

The present argument for the CH pursues the line that the entitlement to each capability should be understood as the entitlement to the social bases of each causal component. And providing or supporting threshold levels of CH entails social action through influencing the social bases of the causal components of each capability. That is, protecting, promoting or restoring the CH of individuals to adequate levels is realized through the possible and justifiable interventions into personal features/needs, conversion skills, external physical conditions and surrounding social conditions.

not met—such as full participation in one’s social world—there is not equal dignity.²¹⁹

In the capabilities approach, resources are directed to ensure a particular capability, which may then lead to an achievement. In line with this approach, we focus on access to rehabilitative technologies for persons with DOCs as a capability intervention to aid in obtaining consciousness and in communication. This intervention can increase the capabilities of, for example, health and affiliation. We do not focus on whether persons with DOCs actually achieve consciousness and communication (which may be impossible), but on whether they have the equality of opportunity to do so. Often, this opportunity will only be available if they have access to the technologies we have described elsewhere in this Article.

The capabilities approach focuses on sufficiency or minimum freedoms.²²⁰ Like our earlier discussion of the legally created expectation of a free, public, minimally adequate education, and like our earlier discussion about the ADA not requiring the most technologically sophisticated or expensive auxiliary aids or devices but instead devices that permit effective communication, we likewise have confined our argument to the minimum rehabilitation necessary to help the brain-injured person with a DOC communicate. As we noted earlier, at least twenty-two percent of persons in a MCS will become fully independent, something only possible with intensive rehabilitation.²²¹ With low-cost interventions, many others may achieve some degree of independence, and at the very least, may be able to be integrated into their communities with increased ability to communicate.²²²

C. Counterarguments and Rebuttals

One compelling objection to our assertion that there is a right to rehabilitative technologies for brain-injured persons with DOC is one of timing. Some may argue that the issue of providing such access is not yet ripe given that many such technologies are currently in the investigational phase, and so may be of uncertain benefit. We assert, however, that because technology outpaces legal and societal responses, our argument is meant to be preemptive and proactive.

Id. at 156.

²¹⁹ *Id.* at 144.

²²⁰ *Id.* at 135.

²²¹ Nakase-Richardson et al., *supra* note 55. One of the issues is that there has not been enough research to know what the likelihood of success would be with this population if diagnosis was better, and if persons had access to all rehabilitative technologies as the standard of care.

²²² See, e.g., SPEAK YOUR MIND FOUNDATION, *supra* note 58 (describing various low-cost devices that assist in communication).

Thus, our argument should be understood as one for current scientific progress as well as an anticipatory argument for future scientific advances. It is never too early to consider the legal underpinning to support access to innovation and to anticipate changes in medical practice, especially when the consequence of neglecting these issues leads to a denial of civil and human rights. Indeed, without the legal argument, the work critical to bringing innovation to the standard of care might not be undertaken or accomplished.²²³ Scientific progress in this domain is moot without correlative access to these developments for patients.

Furthermore, receiving an accurate diagnosis is not an experimental intervention or an exploratory service, which are often not covered by private or public payors, but rather the standard of care for brain injury. An accurate diagnosis is what determines suitability for various rehabilitative interventions, and access to drugs, drug trials, and certain communication devices is part of an emerging standard of care for rehabilitating brain injuries.²²⁴ It may be the case, however, that patients with severe brain injury and subsequent disorders of consciousness will be discharged from the hospital to inpatient rehabilitation in order to perform a proper, in-depth diagnostic assessment.²²⁵

Similarly, some may also argue that by arguing for such access to what currently amounts, in some instances, to experimental interventions, we further the widespread therapeutic misconception that research is equivalent to treatment.²²⁶ It is important to note, however, that we are not arguing for special treatment for patients with DOCs, but parity²²⁷: we argue that patients should receive access to rehabilitative technologies that may assist them in regaining consciousness or communicating with their healthcare providers and family members.²²⁸

223 There is currently enough evidence to suggest efficacy for many of these interventions. See *supra* Section I.B. Furthermore, the dichotomy between research and treatment for this population should not be overstated. *Fins, Technology, supra* note 5, at 896.

224 Admittedly, access to rehabilitative technologies such as deep brain stimulation or communication through neuroimaging is not currently the standard of care for brain injury, but our argument anticipates when such technology may be part of the standard of care.

225 There is a large diagnostic error rate for patients with DOCs. Schnakers et al., *supra* note 70 (citing an error rate of 41 percent). Additionally, given that a patient's status may change over time from a VS to an MCS, even if initial neuropsychiatric testing does not indicate that patients have consciousness, they should be reassessed at a future date so that they are not segregated and isolated when they do have intermittent consciousness.

226 See Paul S. Appelbaum et al., *The Therapeutic Misconception: Informed Consent in Psychiatric Research*, 5 INT'L J.L. & PSYCHIATRY 319, 327-28 (1982) (reporting results of an empirical study of psychiatric patients' attitudes).

227 We address this issue in another paper. See Wright, Ulrich, & Fins, *supra* note 67.

228 We do acknowledge, however, that there is no longer a "simple dichotomy between research and clinical practice upon which so much of our normative and regulatory standards are founded." *Fins, Technology, supra* note 5, at 896; see also *supra* Section I.B. (describing the

Another strong counterargument for providing access to rehabilitative technologies for persons with DOC is cost, both social and economic.²²⁹ This objection or concern pertains both to the auxiliary aids required by the ADA to assist in communication and Medicare policy, as well as any other social welfare changes based on a right to rehabilitative technologies for patients with MCS. It is also a critique of the capabilities approach when phrased as an issue of whether society's goal should be spending a lot of money on a small number of individuals to achieve sufficiency instead of using that money on larger numbers of people to help them flourish, which can look like equalizing downward.²³⁰

In regards to ADA compliance, "Congress expressly determined that the costs of continued segregation of persons with disabilities were outweighed by the benefits of integration—on both an economic and a moral basis."²³¹ As Professor Tucker noted, "The underlying principle of the ADA is that people with disabilities must be fully integrated into society—that we must recognize the potential of *all* members of society, disabled or not, even though it may cost money or impose some burdens upon covered entities to reach this objective."²³²

While Congress determined that making the disabled productive would reduce costs,²³³ this rationale for integration may not apply for the minimally conscious.²³⁴ However, the moral imperative for integration still applies regardless of its cost,²³⁵ although healthcare facilities and providers who decline

evidence of efficacy for some interventions). Access to some interventions is now becoming part of an emerging standard of care. See John Whyte, *Disorders of Consciousness: The Changing Landscape of Treatment*, 82 NEUROLOGY 1 (2014).

229 See Cook, *supra* note 141, at 458.

230 See VENKATAPURAM, *supra* note 21, at 118-19, 137-39, 140-42 (describing critiques of the capabilities approach).

231 Cook, *supra* note 141, at 457.

232 Tucker, *supra* note 142, at 351.

233 Cook, *supra* note 141, at 458.

234 Indeed, Professor Tucker also asserts that the primary rationale of the ADA is to benefit the disabled, and any benefits to society at large through increased revenue from taxes, for example, are bonuses. See Tucker, *supra* note 142, at 350.

235 When describing the passage of the ADA, Professor Cook looks to the legislative history, which shows that political representatives were well aware of the economic costs of the legislation, but that the moral benefits outweighed those costs.

In the legislative history of the ADA, Congress acknowledged that, at least in the short run, the ADA would "impose considerable expenses and rightly so. It is time that we did these things. It is time that we brought persons with disabilities into full freedom, economic and otherwise, with other citizens in our society. This bill will do that. In doing so, we should be aware that it is going to be costly and difficult and that there will be some complaints."

Cook, *supra* note 141, at 464 (quoting Senator Hatch)).

to provide access to rehabilitative technologies for persons with a DOC may defend themselves against a claim under the ADA by arguing that such provision poses an “undue burden.”²³⁶

In regards to changing Medicare policies, which may trigger other healthcare insurers to change their policies, it is an open question as to whether costs will actually increase. While many may point to increased costs in providing physical rehabilitation or neuroimaging, which may have uncertain benefits, they fail to consider that patients with DOCs already incur great costs for health payors, costs that our proposed interventions may actually reduce.²³⁷ Importantly, however, we echo others who have noted that “[a]s issues relating to areas such as insurance and technology are explored, there will also be a financial cost to

236 See also Taylor, *supra* note 172, at 1480-83 (analyzing costs under the ADA and *Olmstead*). In the *Olmstead* opinion, cost was cited as a factor to consider when determining if a particular accommodation for a disabled person would fundamentally alter a state’s program. One way to think about cost is the cost of providing care in a restrictive institution compared to the cost of providing care in a less restrictive institution. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 594-95 (1999). Another way to think about cost, however, and the way the majority asserts is the proper way is to think about costs of providing care to the disabled in relation to the state’s overall program of providing care to persons with disabilities. *Id.* at 597, 603-06.

But we recognize, as well, the States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States’ obligation to administer services with an even hand In evaluating a States’ fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the States’ obligation to mete out those services equitably.

Id. at 597. The Court continued:

Sensibly construed, the fundamental-alteration component of the reasonable-modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.

Id. at 604.

237 See FINS, RIGHTS COME TO MIND, *supra* note 9, at 301-02 (offering an example of a proper cost-benefit analysis); see also Joseph J. Fins, *Deep Brain Stimulation: Calculating the True Costs of Surgical Innovation*, 12 VIRTUAL MENTOR 114 (2010) (arguing that there are huge costs to custodial care for persons with severe brain injury and DOC, and that experimental interventions such as DBS may actually reduce these costs due to offsetting benefits from the DBS; suggesting that by invoking cost arguments to reject interventions for those with DOC is part of systemic bias against those with severe brain injury). Professor Fins has also expressed concern in other work that fears about high costs of technology for neuroscience and treatment of neuropsychiatric disorders may inhibit such research and treatment. See, e.g., Fins, *Technology*, *supra* note 5, at 902.

A RIGHTS AGENDA FOR SEVERE BRAIN INJURY

support those evolving rights.”²³⁸ We assert that the ethical imperative of providing access to communication, which will aid in decreasing segregation and isolation and make integration into community possible, is a social good that far outweighs any monetary costs that may result from changing insurance policies.

CONCLUSION

Writing in the context of same sex marriage, Justice Kennedy recently stated, “[N]ew dimensions of freedom become apparent to new generations.”²³⁹ This is true in the context of disability rights as well. A reflection upon disability law is especially apt at this moment, given that it has been 25 years since the Americans with Disabilities Act of 1990 was passed.²⁴⁰ There has been a new generation of experience with the ADA and a new generation of developments in neuroscience that have expanded the category of disabled and also have expanded available auxiliary aids and services. Thus, there has been ample time for “new dimensions of freedom to become apparent.”

Disability law has evolved over time to emphasize and facilitate maximum community integration for persons with disabilities. Scholars have long noted the “expressive” or “pedagogical” effect of laws,²⁴¹ and in the case of the ADA, the law expresses our aspiration that all persons be part of society and have opportunities to achieve their full potential. As Ben Mattlin observed recently about the ADA in the *New York Times*, it is “about more than ramps and Braille; it’s about dispelling stereotypes, ensuring parity and fairness, creating opportunities and opening up our society to the full spectrum of types and needs. It’s about accepting, even welcoming, a huge and often marginalized segment of the population.”²⁴²

As Professor Fins and others have noted, there is a deep connection between rights and the capability to exercise these rights.²⁴³ In the context of disability, integration is not solely about living in one’s community, but also about having access to “auxiliary aids and services” that will aid in communication. This ability to communicate is vital to any meaningful sense of community

238 Jones, *supra* note 143, at 496.

239 *Obergefell*, 135 S. Ct. at 2588.

240 See *The Americans with Disabilities Act, 25 Years Later*, N.Y. TIMES (July 26, 2015), <http://www.nytimes.com/roomfordebate/2015/07/26/the-americans-with-disabilities-act-25-years-later> (debating the impact of the ADA 25 years after it was passed).

241 Bitensky, *supra* note 101, at 635-637; see Cass R. Sunstein, *On the Expressive Function of Law*, 144 U. PA. L. REV. 2021, 2024-25 (1996).

242 Ben Mattlin, *An Act That Enabled Acceptance*, N.Y. TIMES (July 25, 2015), <http://www.nytimes.com/2015/07/26/opinion/sunday/an-act-that-enabled-acceptance.html>.

243 FINS, RIGHTS COME TO MIND, *supra* note 9, at 292-94 (describing the connection between rights, capabilities, communication, and communities).

participation and inclusion.²⁴⁴

Given recent knowledge about a new class of disabled persons—those with minimal consciousness, a category based on new findings that did not exist when the ADA was originally conceived and passed—we need a new paradigm of community integration. In this Article, we have argued that access to rehabilitative technologies such as neuroprosthetics or pharmacological interventions is necessary to fulfill legal mandates of integration rather than segregation, which is a form of discrimination according to the ADA. As technology and medical science advance, the law needs to keep pace in order to be responsive to new realities. In this case, healthcare providers need to recognize that the ADA applies to patients with a DOC. While the ADA does not mention neuroprosthetics, these clearly fall within the definition of “auxiliary aid” and should thus be provided to persons in a MCS.

We have also argued that such access to rehabilitative technologies is compelled if rehabilitation of the injured brain is viewed as analogous to education of the developing brain, given that children have an expectation of free public education. The purpose of both interventions is the same—to provide beneficial stimulation to a brain that still has much developmental potential and is at a critical point in neurodevelopment. Furthermore, finding a right to rehabilitation of the injured brain based on the expectation of free public education protects against the weakness of statutory rights—the fact that statutes can be amended or revoked.²⁴⁵ As others have noted, “a comprehensive legal theory embodying both constitutional and statutory rights is more likely to serve private and public needs than a theory including just one or the other.”²⁴⁶

Importantly, however, while the right to rehabilitative technologies that will assist in communication is afforded to those with DOCs under the ADA or by analogy to the expectation of a free public education for children, this right may need to be realized through affirmative litigation. Successful realization of these rights may also require accompanying policy changes. Advocates for the

244 Indeed, when writing about group homes for persons with intellectual disabilities, Justice Marshall noted a connection between liberty and community when he stated that “what makes for human freedom and fulfillment—the ability to form bonds and take part in the life of a community.” *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 462 (1985) (Marshall, J., concurring in part and dissenting in part).

245 See Tucker, *supra* note 142, at 388 (“Congress might be more apt to lessen protections granted by the ADA rather than to increase those protections.”). When Congress did amend the ADA in 2008, however, it tried to strengthen protections for persons with disabilities.

246 Fergeler, *supra* note 150, at 779. Writing in the context of intellectual disabilities and institutionalization, Fergeler argues that institutionalization is a violation of procedural and substantive due process and asserts that the institutionalized should be considered a quasi-suspect class for purposes of equal protection analysis. *Id.* Fergeler then argues that institutionalization is rarely rational for purposes of the equal protection analysis even if the intellectually disabled are not treated as a suspect class. *Id.*

A RIGHTS AGENDA FOR SEVERE BRAIN INJURY

minimally conscious should use all available means—petitioning the courts, lobbying the legislature, and educating the medical profession—to achieve the goal of integrating persons with a DOC into their communities to the extent possible.

The problem of segregating the minimally conscious and those who have the potential to recover consciousness to some degree may have been hidden or unrecognized prior to the refinement of the category of DOCs and the development of drugs and devices that can help patients with DOCs.²⁴⁷ Now that we have proper diagnostic categories, are developing treatments for DOC, and are acutely aware that this class of patients has been isolated and segregated, we are obligated legally and ethically to address and overcome their isolation and segregation.²⁴⁸ The liberty, equality, and dignity of these disabled citizens with DOCs are at stake, as is their reintegration into our community.

247 Both the existence of the MCS and interventions for it have been enabled by rapidly changing technology. For a discussion of the relationship between neuroethics and technology, see Fins, *Technology*, *supra* note 5.

248 As the founder of Speak Your Mind Foundation, Dan Bacher, argues, persons with disabilities deserve devices that help them communicate. Speaking about one person in particular, he stated,

They deserve it. Maggie has the right to communicate, just as you or I would . . . [\$30] glasses enable her to interact with the world. Why wouldn't we do that? . . . [These devices] enable many, many others like Maggie to communicate effectively, to express their personalities, to control their environments, to speak their minds.

SpeakYourMind Found., *SpeakYourMind Foundation*, YouTube (Mar. 23, 2014), <https://www.youtube.com/watch?v=oRBPjUOrbd0> (quoted material occurs between 4:00 and 4:15 as well as 5:45 and 5:55); *see also* FINS, RIGHTS COME TO MIND, *supra* note 9, at 301 (describing low-cost communication technologies).

